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## Report of the Public Health Service Task Force on Minority Health Data



U.S. Department of Health and Human Services  
· Public Health Service  
Office of Minority Health

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U.S. PUBLIC HEALTH SERVICE  
Improving Minority Health Statistics

Report of the  
PHS Task Force on Minority Health Data



May 1992



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MINORITY HEALTH DATA  
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## **EXECUTIVE SUMMARY**

### **INTRODUCTION**

America's population of over 250 million persons reflects a remarkable diversity in racial and ethnic composition. In 1990, Black persons, Asian Americans and Pacific Islanders, and American Indians and Alaska Natives combined made up 16.1 percent of the U.S. population. Hispanic persons, who may be of any race, made up nine percent of the population. Moreover, racial and ethnic minority populations are growing at a faster rate than the White population. By the year 2000, racial minorities are expected to make up 17.6 percent of the U.S. population, and persons of Hispanic origin are expected to comprise 11.3 percent.

Racial and ethnic minority populations in the U.S. differ widely in social and cultural characteristics as well as in economic status. Considerable diversity exists within minority populations as well. Minorities are often disproportionately represented among the economically disadvantaged in the U.S. In addition, despite striking advances in medicine and technology, continuing disparities exist in health status and access to care between racial and ethnic minorities and the general population.

In order to assess and understand the causes of racial disparities in health status, and to develop approaches to overcome them, improved and expanded minority health data are essential. Consequently, the Public Health Service (PHS) Task Force on Minority Health Data was established to promote the development of improved minority health data in support of public health assessment, policy development, and programmatic purposes. The objectives of the Task Force were to conduct a short term, forward-looking policy-oriented review of the minority health data activities and plans of the Public Health Service in the light of current and anticipated data needs, identify data gaps and other issues, and make recommendations to the Assistant Secretary for Health for addressing high priority data needs. The Task Force carried out its work under the auspices of the PHS Health Data Policy Committee.

### **BACKGROUND**

Racial disparities in health status and access to health care are a continuing public health concern. In 1985 the Secretary of Health and Human Services' Task Force on Black and Minority Health issued a seven volume report assessing the health status of four generally recognized race and ethnic groups in the United States: Black persons, Asian and Pacific Islanders, American Indians and Alaska Natives, and persons of Hispanic origin. The report documented a "persistent, distressing disparity in key health indicators among certain subgroups of the population" and identified six causes of death that together accounted for more than 80 percent of the excess mortality observed among Black persons and other minority groups. These six causes were cancer; cardiovascular disease and stroke; chemical dependency; diabetes; homicide and accidents; and infant mortality. In addition, to the extent that data permitted, the 1985 Secretary's Task Force Report described the significant

variations in health status among subgroups of the four broad racial and ethnic minority populations.

In September 1990, Secretary Sullivan unveiled the report Healthy People 2000. Like the 1985 Task Force Report, Healthy People 2000 outlined the need for substantial improvements in the health of minority populations in the U.S. and underscored that need by setting special goals for reducing disparities in death, disease, and disability experienced by these groups compared to the white population. Healthy People 2000 also described the available evidence showing the extraordinary diversity in health status, knowledge, attitudes, and practices of subpopulations within these four broad groups.

Despite its scope, the findings of the Secretary's Task Force Report were limited by the data available at that time and did not allow for comprehensive analysis of the health status of minority populations. Similarly, the ability to set meaningful targets for minority populations in Healthy People 2000 was compromised by the limited availability of data to quantify the baseline health status of these groups. Accordingly, both reports emphasized the need to improve health data on racial and ethnic minority populations in the U.S. in order to assess and understand racial and ethnic disparities in health status, and to develop approaches to overcome them.

Both the persistence of racial disparities in key health indicators and the size and anticipated growth of minority populations in future years lend even greater urgency to the need for improved minority health data. Since the issuance of the 1985 Secretary's Task Force Report, AIDS has been added as a seventh disease that disproportionately impacts the minority population in the United States. Further, minority populations continue to suffer excesses of many adverse health conditions, which may not necessarily result in death but do result in a lower quality of life.

## **APPROACH**

The Task Force focused its review in the context of three broad concerns. An initial concern centered on the extent to which existing and planned PHS data activities actually collect and publish statistics for racial and ethnic populations in accordance with government-wide statistical policy standards. The Office of Management and Budget (OMB) has issued a classification for race and ethnicity for use in all federal data collection activities. The OMB standard includes four race categories and one ethnicity category. The categories for race are White, Black, American Indian or Alaska Native, and Asian or Pacific Islander. The ethnicity category includes Hispanic origin. The OMB classification was developed for statistical uses and for administrative and civil rights reporting. It was not intended to be scientific or anthropological in nature. While the classification has limitations, it has been very useful as a uniform standard and is the basis for virtually all minority statistics currently available.



A second area of concern related to the adequacy of the OMB classification to suitably characterize the wide diversity in health and socioeconomic status as well as cultural differences among subpopulations within the four race and ethnicity categories, e.g. Japanese, Koreans, Puerto Ricans, and Cubans.

A third area of concern involved the need to move beyond race and ethnicity data alone in assessing minority health issues. Improved and expanded data on specific racial and ethnic minority groups are essential in identifying health disparities and describing health issues of unique or disproportionate impact on minorities. However, a full understanding of the causes of racial disparities in health requires consideration of socioeconomic, cultural and behavioral factors as well.

The Task Force employed several approaches in addressing its charge. As an initial step, the Task Force considered a number of legislative and policy developments in the area of minority health. In addition, all PHS agencies prepared detailed descriptions of their critical data needs, gaps and issues in minority health from both the programmatic perspective and the broader public health perspective. Within that framework, the Task Force then reviewed minority health data activities and plans of all PHS agencies. To gain additional perspectives on minority health data needs and issues, the Task Force invited public comment through a notice in the Federal Register.

## FINDINGS

Task Force review indicated that, in carrying out their respective missions, PHS agencies sponsor an impressive array of statistical and epidemiological activities which provide data on minority health. Most of these activities include minority data as a component of a general population focus, but some focus exclusively on one or more minority groups. While most minority health-related data activities in PHS are conducted by the National Center for Health Statistics within the Centers for Disease Control, other PHS agencies sponsor a number of significant data activities which provide data on minority populations. The PHS data activities reviewed by the Task Force are described in detail in the accompanying Directory of Minority Health Data Resources in the Public Health Service, developed by the Task Force as a by-product of its work.

While a number of improvements have been and continue to be made in minority health data, the Task Force identified a number of unmet needs and other issues related to minority health data. Unmet data needs, or data gaps, were identified for all minority population groups, and especially for minority subpopulation groups. Minority health data gaps encompass all major areas of health statistics, including population and health status, health resources, health care utilization, and health care expenditures, as well as program management data. Examples of data gaps and issues in minority health are summarized below.

Measuring Race and Ethnicity - Most PHS surveys and epidemiological research activities do include the OMB standard race and ethnicity categories, but some exceptions do exist. In

addition, some PHS data systems which use the OMB standard categories tend to publish statistics for the White and Black populations while combining the other three minority categories into a category labeled "other races." When reliable estimates can be developed for specific population groups, this practice results in a loss of valuable minority health detail.

The Need for Data on Minority Subpopulations - The OMB classification has done much to promote comparable minority health data across federal agencies, but it is a minimum standard. Each of the OMB race and ethnicity categories actually comprises many different subpopulations representing diverse nationalities and cultures. The use of these broad categories in the collection, tabulation, and analysis of minority health data often tends to mask major differences in health status among subgroups within these categories.

Mortality Data - Although birth and death records are a valuable source of data on the health status of minorities, the quality of the race and ethnicity information needs to be improved, and concerns exist about possible underreporting in the American Indian and Alaska Native category. Data on the total Hispanic population in the U.S. are not yet available from this system, even though an item on Hispanic ethnicity has been included on the Standard Birth and Death Certificate recommended for use in each State. National vital statistics information for Asian and Pacific Islanders are also limited. In addition, the absence of reliable denominator data precludes the tabulation and publication of mortality rates and other measures for these populations between decennial censuses.

Morbidity Data - National data on the incidence and prevalence of diseases, impairments, disability and functional status as well as other types of morbidity data on minority populations are limited. Much of this type of information is developed from national surveys and the sample design and size of these surveys are often not adequate to provide reliable data for small numbers of persons or events. Because national surveys typically sample minorities in proportion to their presence in the U.S. population, they usually can provide estimates only for the White and Black populations, and occasionally, for the Hispanic population. Data are not typically available for relatively smaller population groups, such as American Indians or Asian and Pacific Islanders, because they are included in too few numbers to permit reliable analyses of their health status.

Socioeconomic and Risk Factor Data - Data on socioeconomic status are not routinely analyzed as risk factors for poor health status or adverse health outcomes among minority populations. Data necessary to shed light on the risk factors that influence the health status of minorities are either limited or under-utilized. While data on health-related risk factors are becoming more routinely collected in surveys, sample size considerations limit the availability of such data for minority populations. Other factors which influence health status, such as cultural heritage, language barriers and immigration patterns are not routinely included in surveys.



Health Care Utilization and Expenditure Data - Data on health services utilization for minority populations are limited for a number of reasons. Provider-based surveys are based on sample sizes insufficient to permit the development of estimates for most minority populations and subpopulations, and record-based surveys often suffer from incomplete reporting of race and ethnicity. Moreover, the data currently available on access to care and use of care do not encompass the full range of provider types or settings. Health care expenditure data on minority populations are similarly limited.

Health Care Resources Data - While data on the numbers and characteristics of minorities being trained as health professionals are generally available, data on the numbers and practice characteristics of minority health care personnel are extremely limited. National data describing the numbers and types of personnel from whom various minority groups receive their health care and identifying health care settings in which minorities receive their health care are incomplete.

Analysis and Dissemination Issues - In spite of increased efforts to publicize the availability of minority health data, many users are unaware of the kind and amount of data that already do exist. Similarly, the pool of researchers who have an interest in and the capacity to access and analyze minority health data needs to be expanded.

## **RECOMMENDATIONS**

On the basis of its review, the Task Force developed a number of recommendations for addressing data gaps in content and coverage as well as other crosscutting issues in minority health data throughout PHS. The recommendations deal with data planning, collection, analysis and dissemination issues and are grouped into the following eight priority areas or themes:

Organizing and Planning for Minority Health Data -- The Task Force identified limitations in organizational capability to coordinate, direct and provide technical leadership for minority health data activities. Among other recommendations, the Task Force recommends that NCHS establish an organizational unit devoted to minority populations. The Task Force also recommends that the Office of Minority Health strengthen its capabilities in the area of minority health data and establish an ongoing Minority Health Data Advisory Committee. Recommendations one through four address this issue.

Understanding the Causes of Racial Disparities in Health -- To fully understand the causes of racial and ethnic disparities in health status and access to care, it is essential to consider the impact of socioeconomic and cultural factors such as income, education, health behavior, nativity and recency of immigration, all of which have an affect on health status and access to care in minority populations. Recommendations five through seven are directed at this issue.

Improving the Measurement of Race and Ethnicity -- While the OMB standard race and ethnicity categories and definitions are the basis for virtually all of the minority statistics developed by federal agencies, their use is not yet universal. In addition, some agencies are unaware that the OMB standard is a minimum, and that additional detail and flexibility for race and ethnic data is possible within that minimum standard. Further, the classification was not intended to be scientific in nature, and it has other limitations. Recommendations eight through eleven address this problem.

Improving Analysis and Dissemination of Existing Minority Health Data -- While significant gaps exist, an impressive amount of minority health data already has been and continues to be collected. However, much more effective use needs to be made of that existing data. Recommendations 12 through 18 are directed at this issue.

Addressing Data Gaps through Improved Data Collections -- A variety of approaches are needed to address data gaps in minority health that require new data collection. A strategy is recommended which consists of improving vital statistics; oversampling in national health surveys where feasible; conducting special surveys employing followup or dual frame sampling approaches, and sponsoring smaller scale, targeted studies of minority populations and subpopulations. Recommendations 19 through 37 provide more detailed information.

Promoting the Development of State and Community Level Data -- Even when minority health indicators exist on a national level, relatively little subnational data, especially for counties and urban areas, are available for minority populations. In addition, the ability to disaggregate data on minority populations into meaningful geographical groupings such as "communities" or "neighborhoods" is very difficult. Recommendations 38 and 39 are aimed at the development of improved State and community level data on racial and ethnic minority populations, especially data related to Healthy People 2000.

Improving Program Data on Minorities -- Improvements are needed in program management data to assess progress toward minority health program goals. The Task Force recommends that all PHS agencies examine existing and planned program management data systems, whether for research, training or services program administration, for their potential to provide improved data on minority groups. (Recommendation 40)

Improving Data Quality -- The development of high quality data on the health of minority populations raises challenging methodological issues ranging from measurement to overall research strategy and design. A continuing program of methodological research is needed. Recommendations 41 and 42 address data quality concerns.



# CHAPTER I

## INTRODUCTION

### BACKGROUND

To promote the development of improved minority health data for public health assessment, policy development and programmatic purposes, the Assistant Secretary for Health established the Public Health Service (PHS) Task Force on Minority Health Data. The objectives of the Task Force were to conduct a short term, forward-looking, policy oriented review of minority health data plans and activities of the Public Health Service in the light of current and anticipated data needs, identify high priority data gaps and other data issues, and make recommendations to the Assistant Secretary for Health for addressing high priority data needs. The Task Force included representatives of all PHS agencies, and was co-chaired by the PHS Office of Health Planning and Evaluation, the PHS Office of Minority Health, and the National Center for Health Statistics within the Centers for Disease Control. The Task Force carried out its work under the auspices of the PHS Health Data Policy Committee.

The Task Force evolved from the belief that much more must be learned about the causes underlying disparities in mortality, health status, health care access and health care utilization between minorities and the general population. A better understanding of the causes underlying these disparities will enhance the ability of the Federal Government and others to plan, manage and evaluate policies and programs to address these disparities.

### APPROACH

The Task Force employed several approaches in addressing its charge. Agency members of the Task Force described needs, plans, gaps and issues in minority health data from programmatic viewpoints as well as from a broader public health perspective. In addition, the Task Force reviewed major legislative and policy developments relating to minority health as a policy framework for minority health data issues. To gain a broader perspective, the Task Force invited public comment on data gaps and issues in minority health data through a notice in the Federal Register and examined minority data developments at the U.S. Bureau of the Census.

For operational purposes, the Task Force defined the concept of racial and ethnic minority in accordance with OMB statistical policy standards. OMB Statistical Policy Directive 15 outlines a standard classification for race and ethnicity required for use in all federally sponsored data collection and reporting activities involving questions on race and ethnicity.



The categories outlined in the OMB standard classification are:

Race

- o White
- o Black
- o Asian or Pacific Islander
- o American Indian or Alaska Native

Ethnicity

- o Hispanic origin
- o Not of Hispanic origin

It is important to note that the OMB standard is a minimum standard, and that agencies may collect and report additional race and ethnic detail within the groups described as long as the subpopulation detail can be aggregated into the five minimum groups. Further, the OMB classification is not intended to be scientific or anthropological in nature.

As a conceptual framework for identifying data gaps, or unmet data needs, the Task Force considered the needs for and availability of data for each of the minority populations described above, as well as subpopulations, in each of the following major classes of health statistics:

- o population and health status data
- o health resources data
- o health care utilization and access data, and
- o health care financing and expenditure data.

Population data include information on the number, distribution, and socioeconomic characteristics of racial and ethnic populations in the U.S.

Health status data include measures of the nature and extent of mortality, morbidity and disability in persons and populations, as well as their knowledge, attitudes and behavior concerning health and health care.

Health care resources data provide information on the capacity and characteristics of the health care system, including personnel and facilities.

Health care utilization data describe the uses and users of health services and resources, and measure both the volume of use and the persons who use the services.

Health care expenditure data describe the financial aspects of health, and include measures of costs, prices, charges and payments that reflect the financing from both public and private sources to create health care resources and pay for their use.

In its review of legislative and policy developments in minority health, the Task Force sought to define a policy context for consideration of minority health data issues. Examples of documents reviewed were: the 1985 Report of the Secretary's Task Force on Black and Minority Health, Healthy People 2000: National Health Promotion and Disease Prevention Objectives, and the Disadvantaged Minority Health Improvement Act (P.L. 101-527).

- o The Report of the Secretary's Task Force on Black and Minority Health identified six major categories of diseases that caused more than 80 percent of the excess deaths in minority populations in 1979-81: cancer, heart disease and stroke, chemical dependency (measured by deaths due to cirrhosis and liver disease), diabetes, infant mortality, and unintentional injuries (accidents) and homicide.
- o Healthy People 2000 identifies 300 public health objectives for the nation. Over 150 of the health objectives apply to specific racial and ethnic minority populations, and to other special population groups. A variety of data will be needed to monitor progress in meeting the objectives for minority and general populations. In addition, Priority Area 22 outlines a number of specific objectives relating to improved surveillance and data systems.
- o The Disadvantaged Minority Health Improvement Act (P.L. 101-527) emphasizes the need to increase the number of minorities in the health professions and to improve access to health care for minority and disadvantaged individuals. The Act also identifies a number of data gaps and issues in minority health.

As indicated earlier, the Task Force invited public comment from data users and other interested parties concerning data needs, gaps, uses, and other data issues relating to minority health. The major theme identified in the public comments centered on the need for vital statistics, health status and health care access and use data for each of the major racial and ethnic categories outlined in the OMB standard.

Because of the diversity of health and socioeconomic status within minority populations, public comments also reinforced the need for health data on minority subpopulations. Finally, the public comments underscored the need for socioeconomic data, health behavior data, health insurance data and data on country of birth, acculturation, and recency of immigration to more fully understand the causes underlying racial disparities in health.

Subsequent sections of this report discuss trends in the growth and health status of minority populations in the U.S., PHS data needs, resources and plans in minority health data, and data gaps and other data issues in minority health. The report concludes with a series of specific recommendations intended to improve the collection, analysis and dissemination of minority health statistics.

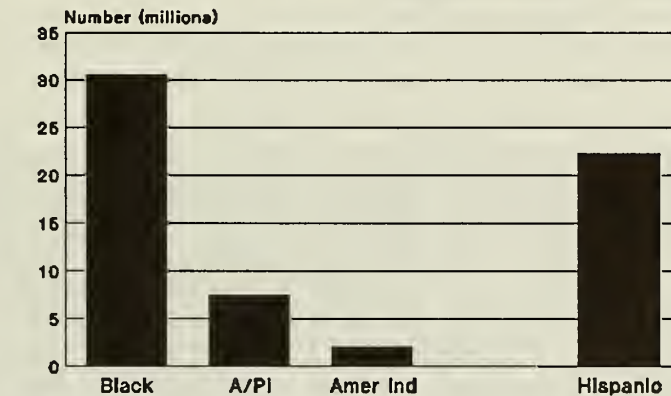
## CHAPTER II

### MINORITY POPULATIONS IN THE U.S.

#### POPULATION GROWTH

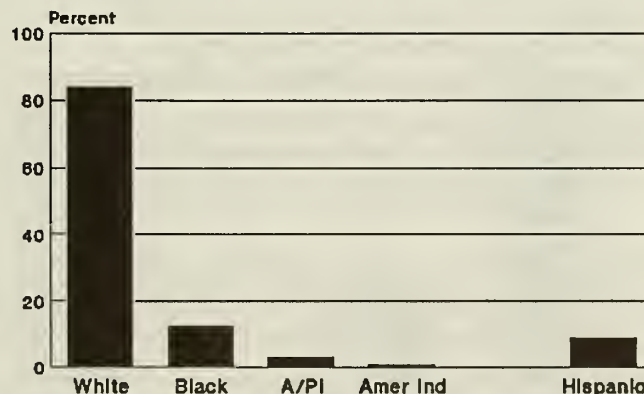
According to the Census Bureau, 16.1 percent of the U.S. population belongs to one of the following racial minority population groups-- Black, Asian and Pacific Islanders, and American Indians and Alaska Natives (figures 1 and 2). Hispanic persons, who may be of any race, comprise nine percent of the population. Over the past decade, the growth of the minority population, as a whole, has been substantially greater than that of the White population (figure 3). Moreover, the growth rate of the minority population is projected to continue to outpace that of the White population in future years.

**Figure 1. U.S. Population  
by race and ethnicity: 1990**



SOURCE: U.S. Bureau of the Census  
1990-CPH-L-74, August 1991

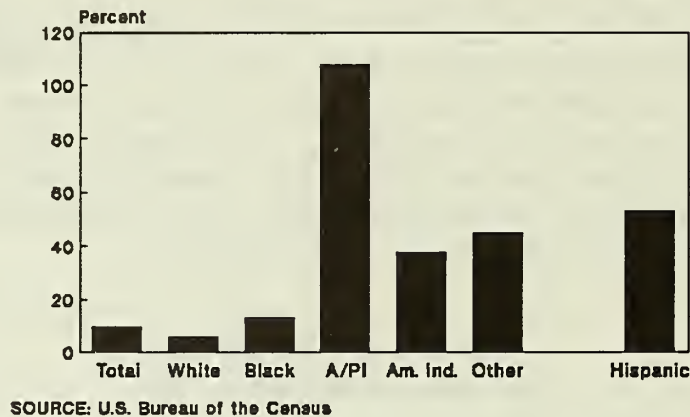
**Figure 2. Percent composition of U.S.  
population by race and ethnicity: 1990**



SOURCE: U.S. Bureau of the Census  
1990-CPH-L-74, August 1991

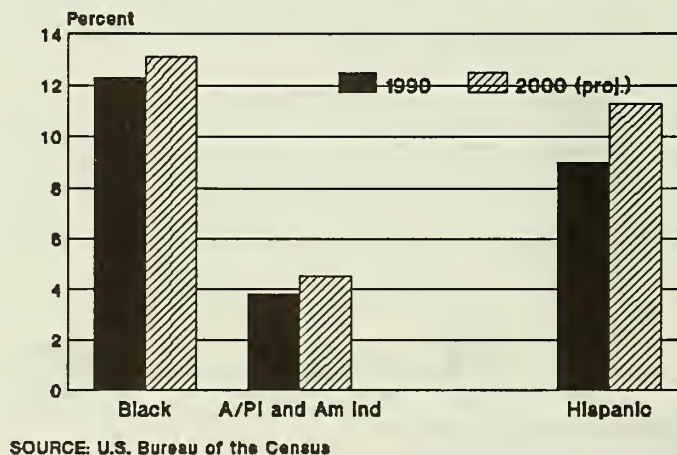


**Figure 3. Percent change in U.S. population by race and ethnicity: 1980-1990**



A major consequence of this growth differential is that the White population will become a smaller proportion of the total population, although the White population will remain the predominant majority. From 1990 to the turn of the century, the White population is expected to decrease in percentage to 82.4 percent of the total population. Conversely, the Black population is expected to increase as a share of the total population from 12.3 to 13.1 percent; Hispanics from 9.0 to 11.3 percent; and Asian and Pacific Islanders and American Indians combined from 3.8 to 4.5 percent--the vast majority of the latter group being Asian Americans and Pacific Islanders (figure 4).

**Figure 4. Percent of U.S. population by race and ethnicity: 1990 and 2000**





Each of these minority populations presents different demographic, socioeconomic, and health status profiles. Moreover, these profiles also vary noticeably among subgroups within these four larger populations. This diversity within each group reflects, to a large degree, the circumstances under which its members came to the United States and their levels of acculturation.

## DEMOGRAPHIC DIVERSITY

In spite of its long-standing presence in America, the diversity among the Black population is considerable, but with less contribution from recent immigration compared to Asians or Hispanics. Over the past decade the growth of the Black population was largely the result of higher natural increase, representing the combined result of a younger population and fertility rates somewhat higher than those of the White population. In addition, rates of immigration for the Black population were slightly higher than those for the White population, primarily as a result of immigration from the Caribbean region.

Composing the second largest minority group in the United States, persons of Hispanic ethnicity come from a variety of different countries. Approximately, three-fifths of these Hispanic Americans are Mexican in origin; about 15 percent are from Puerto Rico; six percent are from Cuba; and about 18 percent are from Central America, South America, and other Hispanic regions. Although persons of Hispanic ethnicity may be of any race, the vast majority classify themselves as "White" in population and health surveys. During the past decade, the increase in size for the Hispanic population was due to natural increase and immigration, just about equally. A high proportion of young adults, as well as higher-than-average fertility rates combined to produce both a high crude birth rate and a low crude death rate, hence the high level of natural increase. At the same time, substantial net immigration from Latin America, primarily Mexico, helped swell the growth of this population.

Like the Hispanic population, the Asian and Pacific Islander population comes from a variety of different countries and is quite heterogeneous. This group includes not only well-established Asian-American groups that are more likely to have been born in the United States, such as Japanese and, to a lesser extent, Chinese and Filipinos, but also large numbers of Eastern and Southeast Asians who have more recently immigrated to the United States. Asian and Pacific Islanders are currently the fastest growing population in the United States. The increase in this minority group over the last decade was due primarily to a heavy flow of immigration from East Asia and Southeast Asia.

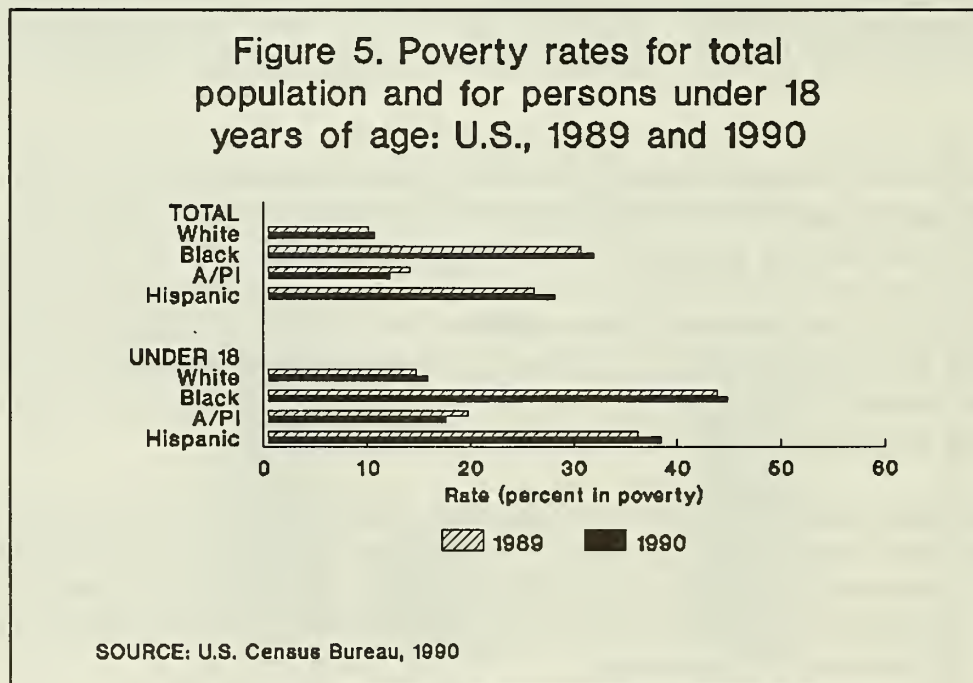
Distributed among about 500 tribes and village units, the American Indian (including Alaskan Native) population composes the smallest but perhaps the most diverse of all minority groups in the U.S. Increases for the American Indian population were attributable predominantly to increases in fertility but resulted in a very small change in the American Indian population's percentage of the total U.S. population.

## SOCIOECONOMIC DIVERSITY

Socioeconomic status (e.g. income, educational attainment, occupation, and employment) is one of the major factors influencing minority health status. Poverty, in particular, has been shown to have a high correlation with adverse health, primarily because it serves to limit or preclude access to needed health services. Poverty rates are based on a set of money income thresholds that vary by family size and composition. Families or individuals with incomes below their appropriate thresholds are classified as below the poverty level. For example, the average poverty threshold for a family of four was \$12, 674 in 1989 and for a person living alone the poverty threshold was \$6,310.

In 1989 the poverty rate for Black persons was 30.7 percent compared to 26.2 percent for Hispanics; 14.1 percent for Asian and Pacific Islanders and 10.1 percent for White persons. In 1990 the poverty rate for Black persons was 31.9 compared to 28.1 for Hispanics; 12.1 for Asian and Pacific Islanders and 10.7 for White persons (figure 5). At the time of the 1980 Census (the latest year for which such data are available), poverty rates for American Indians were similar to those of Black persons and Hispanics.

The poverty rate for persons under the age of 18 was higher than the rate for any other age group. Minority children, in particular, experience high poverty rates. In 1990, the poverty rate was 44.8 for Black children under 18 and 38.4 for Hispanic children compared to 15.9 for White children - all up somewhat from the comparable rates in 1989 (figure 5). The poverty rate for Asian and Pacific Islanders under age 18 was 17.6 percent in 1990.



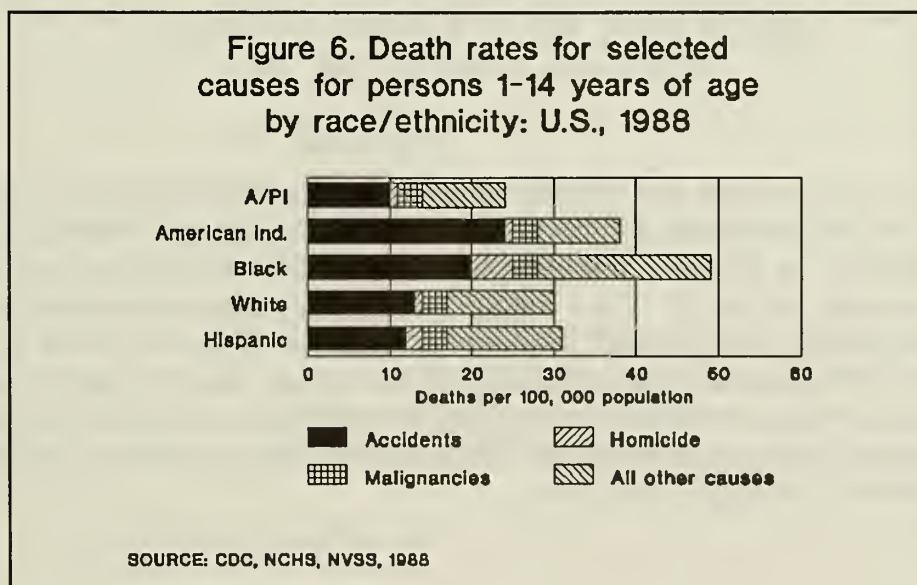


In sum, approximately 40 percent of the nation's poor in 1990 were under 18 years of age, and most of these young people living in poverty were children living in families headed by a female with no husband present. Families with a female head and no spouse present accounted for 53.1 percent of all poor families in 1990, and within each racial and ethnic origin group poverty rates were much higher among families with a female head and no spouse present than among families headed by a married couple. In 1990, the poverty rates for Black and Hispanic families headed by a female with no husband present were 48.1 and 48.3 percent respectively. The comparable rates for Asian and Pacific Islanders and White persons were 22.3 and 26.8 percent.

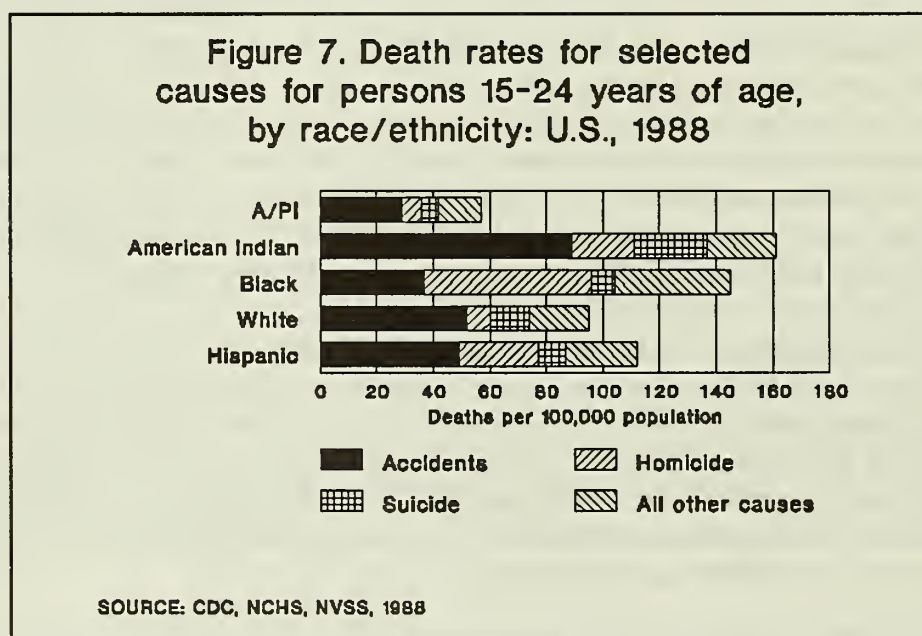
## HEALTH STATUS TRENDS

Since the issuance of the Report of the Secretary's Task Force on Black and Minority Health, the noted disparities in minority health status have increased in some cases, and AIDS has become a major cause of death, especially among the Black and Hispanic populations. However, variations in the age structure of the various racial and ethnic populations, as well as sociocultural and socioeconomic differences among subpopulations within these four categories, make overall comparisons of health status across these broad groups less meaningful. To take note of these differences, health indicators for Black persons and American Indians and for subpopulations of Asian and Pacific Islanders and Hispanics within broad age categories have been published in Health: United States, 1990.

Mortality data indicate that in 1988, death rates for Black and American Indian children 1-14 years of age were much higher than for Asian, Hispanic, and White children of this age. Unintentional injuries were the leading cause of death for children in each race and ethnic group, accounting for about 40 percent of the deaths among Black, Asian, Hispanic, and White children and for about 55 percent of deaths among American Indian children (figure 6). Homicide was the second leading cause of death among Black children, with a death rate three to four times the rate for any other group.

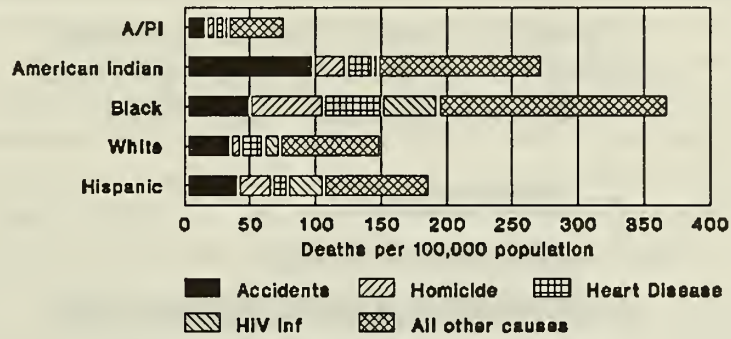


Among persons 15-24 years of age, death rates were highest among American Indians and Black persons, followed by death rates for Asian and Pacific Islanders, White persons and Hispanics. Unintentional injuries were the leading cause of death for all except Black youth 15-24 years old, for whom this cause was the second leading cause of death (figure 7). Among Black youth 15-24 years of age, homicide was the leading cause of death, with the rate being more than seven times the homicide rate for White youth. The homicide rates for American Indian and Hispanic youth, respectively, were about three to four times the rate for White youth. While the suicide rates for Black, Hispanic, and Asian and Pacific Islander youth were lower than the rate for White youth, the suicide rate for American Indians 15-24 years of age was considerably higher.



In 1988 Black 25-44 year olds had a death rate two and a half times the rate for White adults of this age. The death rate for American Indians was second highest, followed by the rate for Hispanic adults. As a whole, 25-44 year old Asian and Pacific Islanders had the lowest death rate--about half the rate for White adults. In this age group, unintentional injuries represented the leading cause of death for American Indians, Hispanics, Asian and Pacific Islanders, and White persons, while homicide was the leading cause for Black persons (figure 8). Human immunodeficiency virus (HIV infection) was the second leading cause of death for Hispanic 25-44 year olds and the fourth and fifth leading causes of death for Black and White persons of this age, respectively.

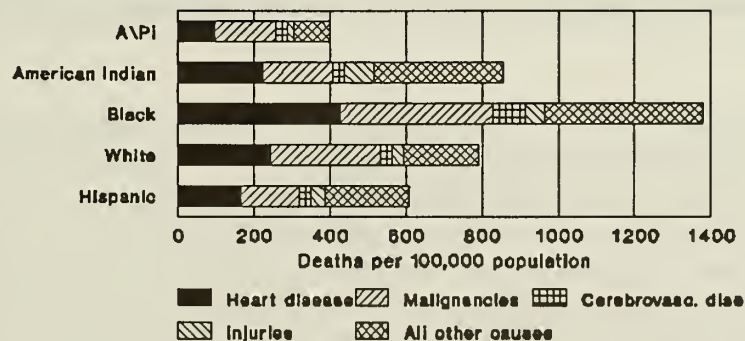
**Figure 8. Death rates for selected causes for persons 25-44 years of age, by race/ethnicity: U.S., 1988**



SOURCE: CDC, NCHS, NVSS, 1988

In 1988, diseases of the heart made up the leading cause of death for Black, Hispanic, and American Indian persons 45-64 years of age and the second leading cause among Asian and Pacific Islanders and White persons of this age (figure 9). Malignant neoplasms were the leading cause of death for the Asian and Pacific Islander and White populations 45-64 years of age.

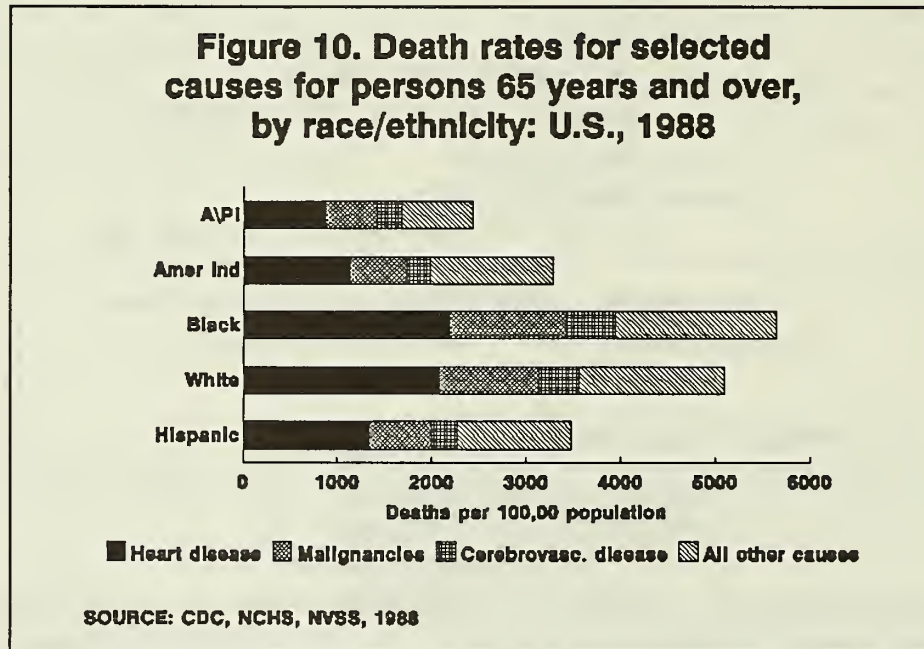
**Figure 9. Death rates for selected causes for persons 45-64 years of age, by race/ethnicity: U.S., 1988**



SOURCE: CDC, NCHS, NVSS, 1988



Death rates for persons 65 years of age and over were highest among Black persons--11 percent higher than for White persons this age, while the rates for the Hispanic, American Indian, and Asian and Pacific Islander elderly population were considerably lower. In each of the minority groups, heart disease was the leading cause of death followed by malignant neoplasms and cerebrovascular diseases (figure 10).



In addition to other causes of death, infant mortality and hypertension continue to be of major concern, especially among the Black population, as are deaths from chronic liver disease and cirrhosis among American Indians. Diabetes presents a significant health problem to Hispanics (Mexican-Americans and Puerto Ricans in particular), Black persons and American Indians. Asian and Pacific Islanders are especially plagued by hepatitis and tuberculosis. In addition, minority populations suffer excesses of many adverse health conditions, which may not result in death but do result in a lower quality of life.

## CHAPTER III

### PHS DATA ACTIVITIES IN MINORITY HEALTH

#### OVERVIEW

In support of its mission to protect and promote the health of the nation's population, the Public Health Service relies heavily on a wide variety of timely and reliable data.

Epidemiological and statistical information is needed on a periodic basis on the health status of the population, on health resources such as personnel and facilities, on access to and the use of health care resources, and on health care financing and expenditures. In addition to public health surveillance and assessment purposes, such information is needed to manage and evaluate public health programs. To meet these needs, PHS agencies have developed a variety of data collection, analysis and dissemination activities.

In carrying out their respective missions, agencies of the Public Health Service sponsor an impressive array of statistical and epidemiological activities which provide data on minority health. These activities are described in detail in the accompanying Directory of Minority Health Data Resources in the Public Health Service developed by the Task Force. Most of these activities include minority data as a component of a general population focus, but some focus exclusively on one or more minority groups.

For the most part, PHS agencies include the standard OMB categories on race and ethnicity in virtually all surveys and epidemiological activities which they sponsor directly. Data from these activities are usually available for the total population, the White population, and the Black population. An overview of the PHS activities and plans in minority health data is presented below in the context of agency missions.

#### OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

The Office of the Assistant Secretary for Health (OASH) is responsible for leadership and direction for all programs of the Public Health Service. In addition to centralized PHS management, policy analysis, planning and evaluation functions, OASH includes several offices which provide both leadership and focal points for selected crosscutting public health issues.

The Office of Minority Health (OMH) is the PHS focal point for the implementation and monitoring of the recommendations of the Report of the Secretary's Task Force on Black and Minority Health and for the formulation and development of policy issues affecting minority health. Established by statute in 1990, the Office works closely with PHS agencies and other agencies of the Department to: 1) establish short and long range goals and objectives and coordinate all other activities within the Department related to disease prevention, health promotion, service delivery and research as they relate to disadvantaged individuals; 2) enter into interagency agreements with other PHS agencies to stimulate and undertake innovative projects; 3) establish a national minority health resource center; 4) support research,



demonstration and evaluation projects; 5) coordinate efforts to promote minority health programs and policies in the voluntary and corporate sectors; 6) develop health information and health promotion materials; and 7) assist providers of primary health care and preventive health services in obtaining the assistance of bilingual health professionals and other bilingual individuals.

The Office of Minority Health also has lead responsibility within HHS for the coordination and development of a plan to implement one of the Secretary's nine Program Directions -- "Improve the health status of minority and low income persons, and reduce disparities in the incidence of premature death, chronic diseases and injuries."

The Office of Disease Prevention and Health Promotion (ODPHP) is responsible for coordination of policies and programs in disease prevention and health promotion. ODPHP is the PHS focus for Healthy People 2000: National Health Promotion and Disease Prevention Objectives. The aim of this prevention initiative is to significantly improve the Nation's health over the next ten years through a comprehensive approach to three broad goals: (1) increase the span of healthy life of Americans; (2) reduce health disparities among Americans; and (3) achieve access to preventive services for all Americans.

Healthy People 2000 sets forth 300 specific and measurable objectives. The objectives include special targets for reducing disparities in death, disease and disability rates historically associated with disadvantaged populations in the U.S. The specific groups targeted are people with low incomes, racial and ethnic minorities, and persons with disabilities. A variety of data are needed on minority groups in order to track progress toward these objectives, and to address data gaps relating to future objectives for specific racial and ethnic minority populations.

The National Vaccine Program Office was established under Title XXI of the Public Health Service Act in 1987 to assume leadership responsibility for the nation's immunization program. Specifically, it was established to "coordinate and provide direction for each element of the immunization process: vaccine development, testing for safety and efficacy prior to licensure, licensing, production, procurement, distribution, delivery and continued evaluation of vaccines in use after licensure. Through collaborative efforts with the Centers for Disease Control (CDC), the Food and Drug Administration (FDA), the National Institutes of Health (NIH), the Agency for International Development and the Department of Defense, the program seeks to promote optimal prevention of infectious disease, assure vaccine availability and use, and identify and resolve vaccine supply and delivery system problems, including access to services.

In coordination with the Health Resources and Services Administration (HRSA) and CDC, the National Vaccine Program is investigating the feasibility of establishing an annual data collection system on the proportion of preschool age children, particularly minority and economically disadvantaged children, who receive age-appropriate immunization. This system would build upon immunization data collection responsibilities under Section 6504 of

the Omnibus Reconciliation Act of 1989. This section requires the annual collection of data on "the proportion of children who, at their second birthday, have been vaccinated against measles, mumps, rubella, polio, diphtheria, tetanus, pertussis, Hib meningitis and hepatitis B."

To the extent feasible, the immunization data system is to be embodied into existing State and federal data development and surveillance activities. The system would be beneficial in targeting resources to meet Healthy People 2000 objectives relating to increasing immunization levels, eliminating measles, diphtheria, poliomyelitis, rubella and tetanus, and reducing the number of cases of pertussis and mumps.

## **CENTERS FOR DISEASE CONTROL**

The mission of the Centers for Disease Control is to prevent unnecessary disease, disability, and premature death and to promote healthy lifestyles. This mission is accomplished through national leadership, applied research (epidemiological, laboratory, and behavioral), public health capacity building, setting of standards and guidelines, and surveillance and statistical analysis.

The National Center for Health Statistics (NCHS) is one of the components of the Centers for Disease Control and serves as the federal government's designated focal agency for general purpose health statistics. Accordingly, most of the general purpose minority health data activities in PHS are conducted by NCHS.

The mission of NCHS is to collect, analyze, and disseminate health data for the United States population on a wide array of health topics such as maternal and infant health, fertility and family planning, chronic diseases and acute illnesses, intentional and unintentional injuries, and utilization of health services.

NCHS obtains information on the health of the U.S. population through the following mechanisms:

- o the National Vital Registration System of births, deaths, marriages, and divorces;
- o Population-based personal interview surveys, such as the National Health Interview Survey;
- o Population-based examination surveys, such as the National Health and Nutrition Examination Survey; and
- o Record-based surveys of health care providers, including hospitals, physicians' offices and nursing homes.

Some of this information is collected annually, while some is obtained on a periodic basis. Occasionally, NCHS also conducts special, one-time surveys. NCHS has also created several special research data files based on existing records.



Collectively, the series of vital registration systems and surveys described above is known as the NCHS Data System. Each component of this system, however, was designed and initiated for a different purpose. Each component therefore varies with respect to its target population, the topics covered, and the frequency of data collection. All of the components obtain information on the race and ethnicity of the persons whose health characteristics are being studied.

From their inception, the various components of the NCHS Data System have been able to provide accurate health statistics separately for the White population and, as a total, for the remainder of the population, under the rubric "all other races." Over the years, changes in sampling design, coding techniques, and other methodologies have enabled most components of the system to provide accurate health statistics separately for the White population and for the Black population. Because of the volume of records involved, birth and death certificates have become a valuable source of epidemiological information on the health of minorities, and much of what is known about racial disparities in health is based on these data systems. Other components of the NCHS Data System are more limited in their ability to provide statistically reliable data separately for racial and ethnic groups, especially those representing smaller proportions of the population.

The procedures that NCHS currently employs for collecting and encoding data on race and ethnicity conform to the OMB standard for race and ethnicity reporting. In some instances, certain components of the NCHS data system are able to provide data for Hispanic and Asian and Pacific Islander subpopulation categories.

Although NCHS follows the OMB standard classification for race and ethnicity reporting, a number of factors affect the ultimate availability and analytical potential of its health data for minority populations. These factors determine whether and in how much detail accurate health statistics can be collected and published by NCHS separately for specific minority populations as well as whether and in how much detail data from NCHS should be analyzed by other users for specific minority populations.

These factors include:

- o Targeted universe
- o Sample size
- o Method of data collection (personal interview, vital records, hospital or medical records, etc.)
- o Question format (open-ended or fixed response)
- o Editing and coding procedures
- o Periodicity of data collection
- o Cost of data collection



Methodological changes over time further combine with these factors to affect the continuity of the available data. The relationship among these factors is complex, varies among the data systems, and has significant implication for the availability of NCHS data on race and ethnicity. Of these factors, the size and design of the sample is a major determinant of the degree to which data on race and ethnicity can be collected or tabulated by detailed minority categories or cross-classified with other variables without diminishing their reliability.

In a sampling design developed to produce national estimates of the health characteristics of the population, such as that used in the Health Interview Survey, proportionately small numbers of Black persons, American Indians, Asian and Pacific Islanders and Hispanic persons fall into the sample population. Therefore, detailed tabulations of data for these minority groups yield estimates with large sampling errors. Estimates of rare health characteristics for minority populations are quite unreliable. Moreover, these statistical concerns are exacerbated for even smaller racial categories such as Asian Americans and subpopulations of this group such as Koreans, or for American Indians. Nevertheless, NCHS has oversampled the Black population and, occasionally, the Hispanic population in its surveys in order to improve the precision of the estimates that can be made for these populations.

Data on race and ethnicity collected through record-based surveys rather than personal interviews, such as the provider-based components of the National Health Care Survey, often suffer from incomplete reporting of this information. Many of the records in these type surveys show "unknown" or have no information entered for the entry "race and ethnicity" and thus severely limit the availability of tabulations about minority populations.

NCHS data are disseminated through various publications and through electronic media, principally public use data tapes. The publications present a wide variety of data from a survey or registration system in a manner considered to be of use to the general audience of users. The amount of racial detail presented may vary from table to table or from report to report. Periodically, NCHS reports address specific topics including minority health issues. For example, Health: United States, 1990 contains a "Chartbook on Minority Health." This Chartbook provides an extensive comparison of selected health indicators among several minority groups. The data in the Chartbook have particular significance because they expand the usual focus on the Black population to include a wealth of new data on Asian Americans and Pacific Islanders, American Indians and Alaska Natives, and persons whose ethnic origin is Hispanic. Journal articles, prepared by NCHS staff often address specific minority health issues also.

Public use data tapes, which are produced at the completion of each data collection activity, permit analysts to examine health variables by racial categories according to specific research needs. The racial categories contained on these tapes may represent the full array of racial detail collected or may be coded into categories less detailed than those collected because of statistical considerations of reliability.

As the federal government's principal agency for the collection of general purpose health statistics, NCHS plays a lead role in minority health data development activities. These activities include continuing to oversample minority populations in its surveys and increasing its publication of data on minority populations. Recognizing the relationship of income, education, and other socioeconomic variables to health status, NCHS has pursued activities to expand its data on socioeconomic status (SES) for minority populations by recommending revisions in the vital record certificates and by including questions regarding SES in a number of national surveys. Additionally, NCHS plays a key role in implementing the objectives in the Healthy People 2000 Priority Area 22, Data and Surveillance. One of the seven objectives in this priority area addresses the need to improve the availability of data on minority populations.

Several provisions of the Disadvantaged Minority Health Improvement Act of 1990 are aimed at improvements in the collection and availability of minority health data, especially for the Asian American and Pacific Islander population and for persons of Hispanic ethnicity. To implement the provisions of this Act, NCHS will be (1) working with States in the Vital Statistics System to collect and code detailed data on ethnic and racial populations; (2) improving the analysis of data specific to particular racial and ethnic populations that is collected under national health surveys, and (3) making grants to public and nonprofit entities to conduct surveys or studies, analyze data or carry out methodological research. The grants will be aimed primarily at supplementing NCHS' efforts to improve the availability of data for subgroups of the Asian and Pacific Islander population, such as Koreans or Laotians, and of the Hispanic population such as Cubans or Puerto Ricans.

Other activities supported by NCHS in response to the Congressional mandate include: (1) providing technical guidelines and incentives to States to improve the level of detail on subpopulations of Asians and Pacific Islanders obtained through the nation's vital statistics system and (2) including a list of nine Asian and Pacific Islander subpopulations in the racial and ethnic categories listed, beginning with the 1992 National Health Interview Survey. In addition, NCHS has entered into a cooperative agreement in conjunction with the National Center for Chronic Disease Prevention and Health Promotion and the Public Health Foundation to award five contracts to State Centers for Health Statistics to analyze unique data sources on minority health and Healthy People 2000 health status indicators.

NCHS and the Office of Disease Prevention and Health Promotion have provided support to the American Indian Health Care Association for assessment of data needs and resources. Further, NCHS has entered into a cooperative agreement with the Minority Health Professions Foundation which will establish a Regional Research Center on Minority Health to promote research activities using NCHS data focusing on health issues affecting Black persons.

In addition to the National Center for Health Statistics, other Centers within CDC collect data from surveys. The Center for Chronic Disease and Health Promotion sponsors the National School Based Youth Risk Behavior Survey. The survey, which includes items on



race and ethnicity, complements State and local Youth Risk Behavior Surveys and is designed to develop estimates of selected risk behavior in adolescents. CDC also supports State Risk Behavior Surveys based on telephone interview surveys by participating States. Most of the State surveys do include the standard question on race and ethnicity.

Other Centers and Program Offices within CDC collect data through disease surveillance systems, including those which report cases of AIDS and other sexually transmitted diseases, tuberculosis and other infectious diseases. Although items on race and ethnicity are included on most case reports, variation in the completeness of reporting appreciably limits their utility as a source of minority health data.

### **ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION**

The Alcohol, Drug Abuse and Mental Health Administration (ADAMHA) holds lead responsibility for the Federal Government's support and conduct of research on mental illness and alcohol and drug abuse disorders. ADAMHA also supports the training of researchers in these areas. This scientific mission is complemented by a mandate to provide national leadership in public health issues associated with mental illness and substance abuse disorders. Accordingly, ADAMHA supports a number of national surveys and epidemiological research activities which provide some information on the incidence and prevalence of alcohol, drug abuse and mental health disorders in minority groups in the U.S., as well as data on risk factors and treatment services associated with these disorders.

The National Institute on Drug Abuse (NIDA) sponsors the National Household Survey of Drug Abuse. Conducted periodically since 1972 and on an annual basis beginning in 1990, the survey is the principal source of reliable national data on the lifetime, annual, and current prevalence of illicit drug use in the general population. Young persons, Blacks and Hispanics are oversampled in the survey to provide more precise estimates for these population subgroups. The annual High School Senior Survey, conducted under a NIDA grant, provides information for monitoring trends in the prevalence of illicit drug use and alcohol use in high school seniors, as well as trends in their attitudes and beliefs. Estimates for Whites, Blacks and Hispanics were published recently.

NIDA also sponsors the Drug Abuse Warning Network (DAWN). DAWN is an ongoing surveillance system which provides information on the consequences of drug abuse as reflected in emergency room episodes for drug related problems and medical examiner cases for drug related fatalities. DAWN surveillance data are available for White, Black and Hispanic populations. The principal source of national data on the alcohol and drug abuse treatment resources in the U.S. is the National Drug and Alcohol Treatment Unit Survey. Intended as a census of all public and private substance abuse treatment units in the U.S., NDATUS provides information on the type and scope of services provided, the sources of funding, staffing and aggregate client characteristics. Survey data are available for Whites, Blacks, Hispanics, and American Indians and Alaska Natives.



NIDA's Treatment Client Data System, currently being implemented in participating States, includes a uniform client minimum data set which contains a set of characteristics about each client. State data will be consolidated at the federal level to provide a national data base. An item on race and ethnicity is included in the data set. In order to study the epidemiology of drug abuse in pregnant women, NIDA is sponsoring the National Pregnancy and Health Survey, a study of women who give birth in hospitals. Questions on race and ethnicity are included.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) sponsors several epidemiological activities which contribute to knowledge of the impact of alcohol use on minority populations. NIAAA supports the enhancement of existing surveys to provide alcohol use data, and to that end has entered into cooperative agreements with NCHS and the Department of Labor. In addition, NIAAA continues its efforts to develop surveys with large enough samples to provide data for minority populations. The National Longitudinal Alcohol Epidemiological Survey, which includes an anticipated 50,000 households, will be NIAAA's strongest effort. Information on race and ethnicity will be obtained.

The National Institute on Mental Health supports a number of research, epidemiological and statistical activities which provide data on the incidence and prevalence of mental disorders, risk factors for mental disorders, mental health treatment resources and the utilization of mental health resources in the U.S. From 1981 to 1984, NIMH sponsored the landmark Epidemiological Catchment Area study, the largest household survey of selected mental disorders ever conducted. The survey provided data on the prevalence of selected disorders in White, Black and Hispanic populations. NIMH also supports "add-ons" to existing NCHS surveys to develop national mental health data linked with general health status information.

NIMH also sponsors the National Reporting Program for Mental Health Statistics. One element of the system is the biannual Inventory of Mental Health Organizations and General Hospital Mental Health Services which collects basic data on the race and ethnicity of the case load in each type of service program. Client level data are collected through periodic sample surveys that include items on the race and ethnicity of clients. A national sample survey of clients in inpatient, outpatient and partial care patients is planned for FY 1993. The feasibility of oversampling for minority groups will be investigated.

National data collection is facilitated through the capacity development activities of the Mental Health Statistics Improvement Program. The program has developed minimum data sets for organizations, clients, human resources, financing and clinical events. The recommended data set for clients includes items on race and ethnicity.

With NIDA and NIAAA, NIMH is sponsoring the National Survey of the Co-morbidity of Alcohol, Drug Abuse and Mental Disorders. The survey will update information on prevalence and risk factors for these disorders in White, Black and Hispanic adult populations. A national survey of mental disorders in children is in the planning stage.

In addition to large scale surveys, all three ADAMHA Institutes support a number of smaller scale, focused research and epidemiological studies on minority populations through their extramural research grant programs in support of knowledge development relating to these disorders. They also support minority research centers and the training of minority researchers.

## **AGENCY FOR HEALTH CARE POLICY AND RESEARCH**

The Agency for Health Care Policy and Research (AHCPR) carries out a program of medical effectiveness research, conducts and supports general health services research, and trains individuals for careers in health services research. Most of these activities, by virtue of the issues and populations studied, include minority populations. During FY 1992, AHCPR also will support several research centers which will investigate the appropriateness and effectiveness of medical care provided to minority populations. Data development and analysis are expected to be a significant part of each center's program.

The periodic National Medical Expenditure Survey, most recently conducted by AHCPR in 1987, is the principal source of national data on health care utilization, expenditures and financing in the U.S. The household component of the 1987 survey included oversamples for low income families, the elderly, the functionally impaired, and Black and Hispanic persons. In addition, in collaboration with the Indian Health Service, NMES included a separate but comparable household Survey of American Indians and Alaska Natives living on or near reservations and eligible for IHS services. A variety of smaller, focused research studies relating to minority health is also supported through the AHCPR extramural research grant program.

## **FOOD AND DRUG ADMINISTRATION**

The FDA is a scientific, regulatory agency responsible for the safety of the nation's foods, cosmetics, drugs, biologics, medical devices and radiological products. The agency's mission is to ensure that: (1) food is safe and wholesome; (2) drugs, biological products, therapeutic devices and diagnostic products are safe and effective; (3) cosmetics are safe; (4) the use of radiological products does not result in unnecessary exposure to radiation; and (5) all of these products are honestly labeled, and that prescription drugs and biologics and restricted devices are honestly advertised.

FDA's data needs concern the practices of the regulated industry and their products, as well as the health effects of these products on the consumer. FDA occasionally conducts consumer surveys and collaborates with NCHS on topics of interest in population surveys, such as NHANES (infant feeding practices and nutritional status) and the National Health Interview Survey (survey of medical device implants).



## HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Health Resources and Services Administration has leadership responsibility for general health service and resource issues relating to access, equity, quality and cost of care. HRSA pursues these objectives by:

- o supporting States and communities in their efforts to plan, organize and deliver health care, especially to underserved urban and rural area residents, migrant workers, the homeless, mothers and children and other groups with special needs;
- o providing leadership in addressing the issues and unique problems related to health care services in rural areas;
- o providing leadership in improving the education, distribution, and utilization of the health professionals needed to staff the nation's health care system;
- o increasing the number of minorities in the health professions;
- o tracking the supply of and requirements for health professionals and addressing professional competence through a comprehensive quality assurance program;
- o providing limited numbers of primary care physicians, psychiatrists, dentists, and other health professionals (obligated to service in return for scholarship aid or loan repayment) to health manpower shortage areas through the National Health Service Corps; and
- o administering the National Organ Transplant Act.

The minority health data needs of HRSA are centered around the specific responsibilities of its bureaus. The Bureau of Health Professions (BHPr) provides national leadership in supporting the development and use of the nation's health personnel and services and as a focus of health care quality assurance and medical malpractice issues. The Bureau administers the Health Careers Opportunity Program, the Centers for Excellence in Minority Health Program, and Student Assistance Programs which focus on improving access to health careers for minorities and other individuals from disadvantaged backgrounds. The Bureau is also the PHS focus for health manpower data collection, analysis and dissemination. To this end, the Bureau develops information on the characteristics and capacities of the U.S. health training systems, analyzes the nation's health personnel workforce, and forecasts supply and requirements under a variety of utilization strategies.

BHPr plans, coordinates, and compiles biennial reports to Congress on the status of health personnel in the U.S., including issues relevant to minority health. The Bureau also maintains the Area Resource File (ARF). This system contains county-level data on health professions, facilities, services utilization, population characteristics and the environment for a wide variety of planning purposes. The Bureau also is conducting a study on rural health care personnel with attention to minority issues, as well as an assessment of available data on health personnel providing services to minority populations, and an analysis of data from the 1987 NMES on access to care in minority populations. In addition, the Bureau has produced and updated several publications providing data on minority health status and health professions training. These publications include: Minorities and Women in the Health



Fields-1990 Edition, Health Status of the Disadvantaged Chartbook 1990, and Health Status of Minorities and Low Income Groups - Third Edition.

The Bureau of Health Care Delivery and Assistance helps assure that health care services are provided to medically underserved populations and to persons with special health care needs. The Bureau serves as a national focus for the development of primary care capacity and for placement of health care professionals in Health Professional Shortage Areas to promote a sustained source of health services. The Bureau also identifies and designates Health Professional Shortage Areas, Medically Underserved Areas, and Medically Underserved Populations.

The Bureau needs information on minority persons served by its primary care grantees and by the National Health Service Corps. Limited data of this type are now available. Accordingly, the Bureau is planning to improve its grant application and reporting systems to develop aggregate data on the services provided with attention to the race and ethnicity of the populations served. The Bureau also is preparing a report to Congress concerning the kind of health care which is available to the Hispanic population in medically underserved areas.

The Maternal and Child Health Bureau is the principal federal focus for planning, implementation, and oversight of the Maternal and Child Health Block Grant and related maternal and child health activities. Little information has been available on the services provided by the MCH Block Grant, but the Bureau is now in the process of implementing annual planning, needs assessment and program reporting requirements that will involve extensive data, including the recipients of Title V services by race and ethnicity, and the type and level of services provided.

The Bureau of Health Resources Development, which administers programs for Organ Transplantation and HIV Services, collects data on minorities as part of the overall data gathering efforts for the Organ Procurement and Transplantation Network and the Scientific Registry of Information on Transplant Recipients. Although plans are being made, there are no data systems currently in place to collect demographic information, including racial and ethnic information, on clients served by the HIV Services Program.

The Office of Rural Health Policy works to seek solutions to health care problems in rural communities. The Office funds seven rural health research centers, two of which are targeting minority populations. The Office of Rural Health Policy also has established a Rural Health Information Center Service, which, as part of its function, will routinely collect minority health and education data.

## INDIAN HEALTH SERVICE

The goal of the Indian Health Service (IHS) is to elevate the health status of American Indians and Alaska Natives to the highest level possible. The IHS eligible population consists of persons of Indian descent belonging to the Indian community served by the local facilities and program. The IHS has responsibility for approximately 62 percent of all U.S. Indians. The IHS carries out its mission through developing and operating a health services delivery system designed to provide a broad spectrum program of preventive, curative, rehabilitative and environmental services. This system integrates health services delivered directly through IHS facilities with those purchased by IHS through contract.

In order to manage its program effectively, the IHS needs accurate, complete and timely data on Indian demographic trends and morbidity, as well as the use of IHS services. Consequently, IHS sponsors a comprehensive health care data system relating to social and economic statistics, vital events, and patient care statistics. The social and vital event statistics pertain to all U.S. Indians. However, the patient care portion of the data system provides morbidity and utilization data only on patients who receive IHS services. To fill data gaps on American Indians in the general population and those in the IHS eligible population, IHS has supported special samples in existing national surveys, in particular, the NMES and the National Maternal and Infant Health Survey.

## NATIONAL INSTITUTES OF HEALTH

The mission of the National Institutes of Health is to improve human health through biomedical and behavioral research, research training, and communications. Virtually all of the components of NIH support minority related health research and research training through targeted minority programs, such as the Research Centers in Minority Institutions Program and the Minority Biomedical Research Support Program, through their regular extramural grant programs, or through intramural research activities.

NIH supports a number of statistical and epidemiological activities which provide data on minorities, including collaborative arrangements with NCHS survey programs, disease or treatment registries, community-based epidemiological studies, and data bases relevant to research grants administration and research training. Examples include the Surveillance, Epidemiology and End Results Study (SEER) conducted by the National Cancer Institute, the Honolulu Heart Program, the Stroke Data Bank, and the Multi-Center AIDS Cohort Study.

NIH also operates three program-oriented data systems. The IMPAC system contains information on grant applications useful to those managing the peer review process as well as to program managers. IMPAC makes it possible to estimate the number of minority investigators who are principal investigators, based on the personal data page submitted on a voluntary basis with grant applications. Abstracts from funded research projects can be obtained from the CRISP system. CRISP can provide information about the types of research supported by NIH, such as the number of grants supporting gall bladder disease in Hispanic populations. NIH also maintains the NIH-ADAMHA Consultant File, which

contains information on 8000 individuals who can be used as experts by NIH and ADAMHA.

In 1990 ADAMHA and NIH issued a policy statement requiring the inclusion of minorities in study populations in extramural research supported by the agencies. The policy is aimed at the inclusion of minorities in general population studies, but also encourages attention to gaps in knowledge about specific U.S. racial and ethnic populations and health problems that significantly affect them.



## **CHAPTER IV**

### **DATA GAPS AND ISSUES IN MINORITY HEALTH**

#### **OVERVIEW**

This chapter focuses on data gaps and issues in minority health. While improvements have been made, a number of gaps and issues remain in the availability of data on the health status of racial and ethnic minority populations in the U.S. In general, a wide variety of health data are available for the White and Black populations. Considerably less national data are available for the Hispanic population, but improvements are underway. Selected health data are available for the larger Hispanic subpopulations, but in general such data are quite limited.

Very limited data are available on the Asian and Pacific Islander population in the U.S. Available data are rarely national in scope and what aggregate data do exist tend to mask considerable diversity among the major Asian American and Pacific Islander subpopulations, such as Chinese, Japanese, Korean, and more recent immigrants from Southeast Asia. Similarly, national data on the total American Indian population are limited. While extensive demographic and health care data are available from the Indian Health Service on its user and service eligible population, there are no national data on the health status (morbidity and risk factor data) of the total American Indian population in the U.S., nor is such information available according to tribal affiliation. Data gaps in specific subject areas of minority health are discussed in detail below.

While the Task Force focused primarily on minority health data gaps and issues at the national level, this focus in no way minimizes the recognition of the need for State and community level data on minority populations. Indeed the lack of minority health data at these subnational geographic levels is considered, in and of itself, a serious data gap.

#### **GAPS IN MONITORING, ASSESSMENT AND SURVEILLANCE DATA**

##### **HEALTH STATUS DATA**

Health status data describe the well being or ill-health of the population so that interventions for preventing and controlling disease can be determined and implemented and the impact of these interventions evaluated. A wide variety of measures are included under the rubric health status, including mortality and other vital statistics information, morbidity data and risk factor data. Data on health status are developed from a variety of different sources, and issues of data availability, and conversely, data gaps vary considerably depending upon the source.

### Mortality and Other Vital Statistics Data

For the most part, health status is often described in terms of statistics on deaths and, to a lesser extent, births, marriages and divorces. One reason for this approach is the availability of these data, which are based on the large volume of records from the U.S. Vital Statistics Registration System. Although States generally revise their certificates approximately every ten years, vital records are limited in the amount of information they can contain. Over the years, improvements in the collection of vital statistics data on minority populations have been introduced, but several issues related specifically to the collection and coding of vital statistics data on minority populations can be identified and are discussed below.

Quality coding of data on race and ethnicity - Reliability is one of the most important but often overlooked issues relating to data availability. The reliability of data on race and ethnicity becomes of particular concern when this information is obtained from records that may be completed by someone other than the individual of interest. In spite of efforts to train registrars, physicians, funeral directors and medical examiners, methodological research reveals inaccuracies in the classification and coding of race and ethnicity on vital records. One reason may be that individuals who fill out death certificates and birth certificates do so inadequately because of insufficient understanding of the importance and uses of the information.

National data for Hispanics - As a result of revisions to the U.S Standard Birth and Death Certificate in 1989, the number of States collecting and coding information on Hispanic origin has increased. However, this information is not as completely reported in some States as in others and the wording of the question on the vital record is not the same among all States. These two factors restrict the availability of vital statistics data for the total U.S. Hispanic population.

Occupation and industry coding on death vital records - Although death certificates are relied upon heavily as a source of health status data, these records contain limited information about the decedent. Information on occupation and industry are two important items about the decedent contained on death records. Nevertheless, not all States code the occupation and industry data and forward it to the National Center for Health Statistics for tabulation. In some instances, the data are coded but States do not have the resources to provide the quality of coding needed to produce data comparable to that needed for inclusion in a national data base.



### Morbidity Data

Morbidity data include statistics related to the incidence and prevalence of diseases, impairments, disability and functional status. While the array of morbidity data is considerable, the amount of such data available for minority populations is quite limited. Virtually all morbidity data currently are based on national surveys and the sample design and size of these surveys are not adequate to support detailed analysis of these conditions in minority populations. Because national surveys sample minorities in proportion to their presence in the U.S. population, they provide more data on the Black population than other minority populations since it represents the largest minority group. Smaller groups, such as American Indians or Alaska Natives, or Asian or Pacific Islanders are included in too few numbers to permit much reliable analyses of their health status.

Some of the most salient needs for morbidity data on minority populations are described below. However, the approach to obtaining these data presents a number of complex considerations that vary according to the minority population under consideration.

Many chronic diseases, disabilities and impairments do not exert a high death toll but do affect minority populations disproportionately and contribute dramatically to a diminished quality of life. For example, Black persons, Hispanics, and American Indians are at high risk for glaucoma and diabetic eye disease and provide examples of areas in which incidence data are needed. Another example is the substantial burden of rheumatic diseases in Eskimos. Limited data can be obtained for these and other similar diseases manifested among minority populations. Virtually no data are available for rarer chronic diseases that may affect minorities disproportionately or exclusively, such as lupus erythematosus, a disease that occurs more frequently in women than in men and three times more frequently in Black women than in White women.

While some national surveys oversample the Black and Hispanic populations in order to increase the precision of the estimates that can be made about these two groups, the sample sizes of national surveys restrict the availability of detailed cross tabulations of morbidity data for any minority group. For example, data on the prevalence of diabetes (diagnosed and undiagnosed) has been published for the Black population by age and sex. However, the sample size of the National Health Interview Survey, even after oversampling the Black population, is insufficient to support more detailed analysis on diabetes taking into account other variables such as onset, availability of medical care, education, socioeconomic status and other co-morbidity factors such as hypertension.

Data on infectious diseases for minority populations are not typically developed from population-based surveys and are particularly deficient for minority populations. The limited data that are available suggest that minority populations suffer higher infectious disease morbidity than the White population. Sexually transmitted diseases such as syphilis and gonorrhea and infectious diseases such as hepatitis B, tuberculosis and measles are examples of concern. However, little data are available about such diseases for minority populations because of the incomplete reporting of race and ethnicity in the systems on which these data



are based and because of the varying procedures used among States for reporting these diseases.

Similarly, ongoing data on immunization status and morbidity from infectious diseases are needed at the national and State level. For example, despite exceptional progress in the control of measles since the licensure of measles vaccine in 1963, the nation experienced marked increases in measles cases and a number of urban epidemics of measles during 1989 and 1990. The primary groups experiencing the epidemic were inner city minority populations.

The NCHS data systems are multipurpose in nature and as such are not designed to provide data sufficient to answer very specific questions about diseases or other health status issues for any population. Thus these systems are not the vehicle for indepth analysis of specific minority health issues. Nevertheless, most data from these systems are presented in terms of minority versus majority comparisons. Little data are presented emphasizing the similarities and dissimilarities of subpopulations within major race and ethnic categories. Moreover, little data are available on minority-specific health issues. This is especially true in the area of environmental and occupational health. Lead poisoning in inner-city children and pesticide exposure in migrant workers, a large number of which are racial and ethnic minorities, provide good examples. Even less data are available that describe areas of "positive" health status among minority populations and those factors that may be associated with their good health.

#### Data on Risk Factors

In addition to data needed to describe the health status of the population, more data are needed to ascertain the determinants of health. Data are needed to help determine why significant gaps in health status persist. Risk factors are the characteristics of individuals that are associated with the occurrence of health problems. The identification of risk is important to elucidate possible etiologic factors for a disease and to plan and develop appropriate preventive measures or educational interventions. Race and ethnicity are important variables in the generation of hypotheses to determine risk. When differences in health status between racial and ethnic populations are observed, the differences usually represent the contribution of a number of other factors such as income level, education, occupation, acculturation, stress or discrimination which affect health status in a positive or negative way.

Like morbidity data discussed above, the potential sources of risk factor data are also quite varied. Accordingly, the method of data collection presents a number of complex issues that vary according to the minority population under consideration. Nevertheless, some specific issues relating to the type of risk factor data available for minority populations emerge. For example, more data are needed to support studies of the knowledge and attitudes that influence or mitigate against the practice of positive health behaviors by minority persons and to clarify whether risk variables that contribute to the occurrence of disease in White populations contribute to disease differently in minority populations. Included among such

data would be health-related knowledge, attitudes, and behaviors related to smoking, nutrition, exercise, and alcohol and drug consumption.

Socioeconomic and sociocultural factors play an important role in the maintenance of health, perception of illness, and the pattern of treatment sought by the individual. Various studies indicate that occupation and low income are factors limiting access to health insurance coverage, one of the most serious barriers to seeking health care. In addition, many other factors such as immigration patterns, cultural heritage and acculturation interact to affect health status. However, little or no valid and reliable measures of acculturation and sociocultural indices that are sensitive to shifts in beliefs, values, and behavior patterns that might increase risk of various diseases in minority populations are contained in current surveys. In addition, wider use of the contributions of other disciplines such as sociology, psychology and cultural anthropology could help identify additional "health-related variables" related to measuring acculturation, assimilation, racism, stress, coping, poverty, wealth, and other variables that could help shed light on factors that influence the health status of minorities. Unfortunately, no surveys were identified which systematically include data on these types of socioeconomic and sociocultural factors.

## POPULATION DATA

Numbers and demographic characteristics of the population are of great importance in any discussion of health status data or risk factor data because population data form the basis for analyzing nearly all of the health characteristics in other data sets. Once the population specific or relevant to the disease or other health characteristic under study is determined, it can serve as the denominator used in constructing meaningful statistical measures, such as rates, ratios, and percentages.

Most of the data on the population of the United States as a whole and of its subgeographic units are published by the U.S. Census Bureau, based on data collected in the Decennial Census, the Current Population Survey (CPS) and other annual or periodic censuses and surveys. Data from the decennial censuses provide the denominators for most of the health status data from PHS data systems in decennial census years. In addition, data from the decennial censuses are a key component of the estimates and projections of the U.S. population which provide the denominators for health status measures in intercensal years.

Although the collection of vital statistics and survey data for the Hispanic, Asian and Pacific Islander, and American Indian populations have been expanded over the years, the absence of reliable denominator data preclude the tabulation and publication of mortality rates and other measures for these populations during intercensal years. For programmatic purposes, the Indian Health Service does develop intercensal and postcensal population estimates for IHS service areas and for the national American Indian population.



## HEALTH RESOURCES DATA

Health resources refer to the personnel and facilities that deliver health services. The Health Professions Reauthorization Act of 1988 specifically addresses the concern for more information about the health care resources available and accessible to minority populations. The Act mandates "studies determining by specialty and geographic location the number of health professionals (including allied health professionals and health care administration personnel) who are members of minority groups, including Hispanics, and studies providing by specialty and geographic location evaluations and projections of the supply of, and requirements for, health professionals (including allied health professionals and health care administration personnel) to serve minority groups, including Hispanics." The evaluations and projections of the supply and requirements for personnel to serve minority groups are extremely difficult given the data that are currently available.

National data describing the numbers and types of personnel from whom various minority groups receive their health care and identifying health care settings in which minorities receive their health care are incomplete. Data on the location of and types of services provided in health facilities such as hospitals, physicians offices, nursing homes, and hospices are generally available but are of little use in analysis of minority health care access issues without a methodology for defining a minority community. Community and migrant health centers provide services to substantial proportions of minority populations and they are the focus of a number of provisions of the Disadvantaged Minority Health Improvement Act of 1990. However, systematic efforts to collect data which would describe the race and ethnicity of the community to be served by these centers and the current users of services have just recently begun.

There is a need for monitoring and assessing the extent to which minority populations have financial and geographic access to health care services in general and to minority and other culturally sensitive health service providers in particular. Data collection mechanisms that are currently used for assessing health care resources and services utilization and other measures of access do not collect data on the race, ethnicity or bilingual ability of providers of care. The collection of such data is essential to efforts to evaluate the Department's effectiveness in carrying out several provisions of the Disadvantaged Minority Health Improvement Act. Moreover, such data are fundamental for studies attempting to assess the relationships between the health care providers' knowledge of and sensitivity to the patient's culture and language as well as factors such as treatment patterns, patient compliance, care seeking and utilization patterns and, ultimately, health status.

While data on the numbers and characteristics of minorities being trained as health professionals are generally available, data on the numbers and practice characteristics of minority health care personnel are extremely limited. With the exception of data for registered nurses, which are available from periodic and costly sample surveys sponsored by the Bureau of Health Professions, there has never been a systematic and comprehensive mechanism for collecting reliable data on the numbers and characteristics of persons of racial and ethnic minority groups who are practitioners in the health fields. Not only has Congress



mandated studies providing such information in the Health Professions Reauthorization Act of 1988, but accurate data on the numbers of minority health care personnel are necessary for measuring the progress that has been achieved in increasing the numbers of underrepresented minorities in the health professions - a federal goal for a number of years.

The decennial census and the Current Population Survey provide some indication of the numbers of minority health personnel. However, data from both of these sources are limited because the occupational data come as a byproduct of the collection of general population data. Thus, occupational classification is based on self-reported job title and job description, not on licensing, certifications, and specialized training. This results in a systematic bias in classifying respondents into occupations of higher status. Also, for many of the health occupations the size of the workforce is relatively small and sampling error can be a substantial limitation, particularly when the focus is on subgroups which comprise a small percentage of the occupation (as is the case with minorities). In addition, census occupational data are only available every 10 years and CPS data only provide estimates for Blacks and Hispanics in the health care work force. Moreover, minority personnel data derived from the census and CPS do not provide information on practice patterns, medical specialty, geographic location and similar data necessary for assessing minority health care personnel and their roles in minority health care.

For many of the health care occupations, particularly allied health but also professions such as pharmacy, optometry, and podiatric medicine, a major factor affecting the lack of data on minority personnel is the lack of timely and systematic data collection efforts for the occupation as a whole. For others, such as medicine and dentistry, where there are systematic data collections by a professional association and a fairly rich data base on the profession as a whole, data collection efforts have not attempted to obtain or have not been successful in obtaining reliable data on the race or ethnicity of practitioners. Efforts by the American Medical Association are underway to improve the quality of their Masterfile data on minority physicians so that data on minority physicians will be available similar to that available for all physicians in the near future. In other efforts to obtain reliable data on minority health care personnel, HRSA is contracting with several professional organizations representing minority health care personnel in order to obtain data from and assess the utility of the information in their databases on Black physicians, Hispanic physicians, and American Indian dentists. The National Medical Association is currently developing a system to provide statistical projections of the number of Black physicians in the country.

Beyond the issue of the actual numbers of minority health care practitioners, there are the issues of measuring their death and retirement rates, the degree of their employment, geographic mobility, and other factors which have a bearing on their current and future availability for providing health care. Yet, there are no mechanisms at present for the comprehensive collection of such information.

For health personnel and facilities data to be most useful in measuring the degree to which minority populations have access to health services, data on the health care delivery systems in areas that are defined as minority communities must be available. The Report of the Secretary's Task Force on Black and Minority Health highlighted the need for specific targeted attention to individual minority communities in order to determine the availability of health professions resources and the general adequacy of health services to specific minority population groups. However, no methodology for defining a minority community has been developed. Previous attempts to conduct analysis using the concept of minority communities have relied on county level data. Unfortunately, highly localized areas of underservice, especially within cities, may be masked in county level estimates by generous provider supplies available in other parts of the county. This is especially problematic since minority populations reside overwhelmingly in urban areas.

#### HEALTH CARE UTILIZATION DATA

Comprehensive, national data are needed on access to care and use of care by racial and ethnic minority populations. Utilization data are needed to:

- o assess and monitor access to care among minority populations;
- o relate health status to health care use;
- o understand and overcome barriers to utilization; and
- o allocate health resources equitably.

To be most useful, health care utilization data must be comprehensive in terms of health care settings, providers and population coverage, and complete with respect to individual utilization patterns. An important need in minority health care utilization data is a description of the types of health care delivered to racial and ethnic populations by various types of providers.

Health care utilization may be categorized into the following modes of medical care: (1) ambulatory care; (2) inpatient care, and (3) extended care. The examination of utilization data allows an understanding of which parts of the health care system are used, to what extent, by whom, for what, and why. Current health care utilization data are limited in terms of comprehensiveness and completeness. This is true for the general population, and especially true for minority populations and subpopulations. While PHS sponsors a number of general purpose provider-based surveys, these data systems do not yet encompass the full range of provider types or settings, nor do they contain sufficient sample sizes to permit the development of estimates for minority populations and subpopulations. Further, many of these provider-based surveys rely on medical records, which often do not contain sufficient information on the race and ethnicity of the patient or client.



Similarly, cross sectional surveys of the population do not encompass the complete utilization pattern of an individual over time, nor are sample sizes large enough to support estimates for minority populations. The rare approaches which comprehensively do follow the health care use of a population over time are unable to provide estimates for smaller subgroups of the population.

Most available national health care utilization data are limited to the White and Black populations, although limitations exist even for the Black population. Increasingly, data are becoming available for the Hispanic population, but available data are still quite limited. Health care data for Asian and Pacific Islanders are very limited. Similar data for Hispanic and Asian and Pacific Islander subpopulations are even more limited. Health care use data for American Indians and Alaska Natives are limited to data developed by the Indian Health Service on its own user population and, to a limited extent, on the IHS eligible population through the Survey of American Indians and Alaska Natives. Virtually no health care use data are available for the American Indian population generally.

Administrative records from program oriented data systems could serve as an important and rich source of information on health care utilization by minority groups, at least for the specific program population. Unfortunately, this potential has not yet been realized. Aggregate service statistics are available on race and ethnicity for IHS programs and for several HRSA service programs. However, administrative and claims records for the Medicare program are not yet able to provide utilization data for minority populations. For the Social Security program and Medicare program, detailed race and ethnic coding began only with those applying for Social Security numbers in 1980. Prior to 1980, the categories were limited to the categories of White, Black, other and unknown. Similarly, while systematic Medicaid program data would provide very useful information on health care use by this population, administrative data for the Medicaid program generally are extremely limited.

There is a lack of minority behavioral data, and a lack of understanding of the effect of health care utilization on minority health. Economic disadvantage, especially low income, appears to be a strong predictor of health status, health care use and health outcomes, but there is limited understanding of the complex processes and factors which influence the pathways to unfavorable health outcomes. Delayed use of health care, organizational and financial barriers, and knowledge, attitudes and beliefs have been defined as a set of interrelated factors which influence access, use and outcomes.

In addition to economic status and health knowledge, attitudes and behavior, data are needed on other factors related to race and ethnicity which may pose barriers to access and health care use for diverse minority populations and subpopulations. Much more information is needed on how immigration status, acculturation, language and cultural factors may affect access to care, patterns of health care use and outcomes in specific minority and ethnic subpopulations.



## HEALTH CARE EXPENDITURE AND FINANCING DATA

Information on the financial aspects of health care describes the financing sources, levels and relationships which both create health care resources in the U.S. and pay for their use. Such data are needed to assess and monitor access to care as a function of health insurance and economic status, to understand and overcome financial barriers to access and care, especially among socially and economically disadvantaged populations, to relate health status and health care use to financing factors, and to allocate resources equitably.

Health care expenditures and financing data are one of the most complex elements of the nation's health statistics system. Comprehensive information is needed on who pays how much for what health care. Aside from the annual economic analyses of national health expenditures developed by the Health Care Financing Administration, the major source of national data on health insurance coverage and the level, source and distribution of health care expenditures in the U.S. is the National Medical Expenditure Survey (NMES), conducted on a periodic basis by the Agency for Health Care Policy and Research.

NMES surveys were conducted in 1977 and 1987, and the next survey is scheduled for 1996. NMES surveys are very comprehensive in terms of health care use and expenditures, source of payment and insurance status over the course of a year, but they are conducted infrequently, and estimates are not available for all minority populations. The 1987 survey is capable of providing estimates for the general population, the White and Black populations, and for Hispanics generally. However, very little information is available for Hispanic subpopulations, Asian or Pacific Islander populations and subpopulations. Information on health care use and expenditures among American Indians and Alaska Natives eligible for IHS services residing on or near reservations is becoming available from the Survey of American Indians and Alaska Natives, a component of NMES.

Although they are limited, available data indicate disparities in health insurance coverage between the general population and racial and ethnic minority populations. Similarly, minority populations are disproportionately represented among the medically indigent and the low income uninsured and underinsured populations. If these disparities in health insurance coverage are to be understood and overcome, more frequent and more comprehensive data will be needed on health expenditures for minority populations and subpopulations.

## GAPS IN PROGRAM MANAGEMENT DATA

Program management data refer to information needed to assess the performance of PHS programs in terms of minority health objectives. Such data are sometimes referred to as administrative data. Examples of program management data include information on number and type of clients served, number and type of services provided, number of research grants awarded, and number of research trainee grants awarded.

In addition to programs concerned with the direct and indirect provision of health services to minority populations, most PHS agencies have some other type of program targeted to

minority populations, such as training and research grant programs. Program management data needs and gaps of the PHS Agencies are summarized below.

The Alcohol, Drug Abuse, and Mental Health Services Block Grant administered by ADAMHA can be a rich source of data on minority populations. However, ADAMHA does not yet have authority to require data from all States on clients and services supported by the block grant. The Agency expects to collect some of this data from its State Systems Development Program currently under development. In addition, ADAMHA needs improved data on minority representation in its extramural research and research training programs. Similarly, AHCPR needs improved data to monitor the representation of minority groups in the health services research and research training which it supports. CDC collects data on race and ethnicity in most of its surveillance systems, but data are also needed on the services provided and clients served under the Preventive Services Block Grant Program.

Programs of HRSA help assure that health care services are provided to medically underserved populations and to persons with special health needs through categorical grant programs, such as the Community Health Centers and Migrant Health Centers Programs, and the National Health Service Corps. While aggregate statistics are available on the minority representation of clients served by some of the programs, improved race and ethnic data are needed to assess the impact of these programs and evaluate their accomplishments in minority health. In the Maternal and Child Health Block Grant program, data are needed from all States on the recipients of services by race and ethnicity and on the types and levels of services provided.

The Bureau of Health Professions within HRSA supports efforts to increase the number of disadvantaged and underrepresented minority individuals who become health or allied health professionals. The Bureau collects and analyzes data and disseminates information on the characteristics and capacities of U.S. health training systems and assesses the nation's health personnel workforce, forecasting supply and requirements under a variety of utilization strategies. All Divisions of the Bureau either have in place or are planning systems to obtain racial and ethnic minority data on participants in Bureau grant programs.

The Bureau of Health Resources Development within HRSA has a major program dealing with HIV services. The AIDS program is responsible for the AIDS Service Demonstration Projects and AIDS Drug Reimbursement program. A data system is being planned that will enable the Agency to monitor grantees in terms of cost of providing services, demographic characteristics of clients receiving services, and if feasible, the transmission category, stage of HIV-related illness, and insurance status of clients.

The Division of Organ Transplantation manages a program of grants to organ procurement organizations and other nonprofit entities to increase the number of organ donors in the United States. The program also supports the National Organ Transplantation Network, designed to ensure equitable distribution of available organs to patients and transplant



centers, and a Scientific Registry of demographic and clinical information on transplant recipients. All of these programs need improved data on minorities.

The Indian Health Service operates a health services delivery system designed to provide a broad-spectrum program of preventive, curative, rehabilitative, and environmental services. In order to manage its program effectively, the IHS needs accurate, complete, and timely data on Indian demographics and morbidity. Most of the IHS health data needs are met through its information systems and data bases. Inpatient and outpatient care statistics are derived from IHS reporting systems. IHS has other information systems which are the source of program statistics for the different services that IHS provides. These include: Dental Reporting System, Environmental Health Reporting System, Chemical Dependency Management Information System, and the Community Health Representative Information System.

The IHS patient care information systems provide morbidity and utilization data for Indian patients that are accessing the IHS system. Although these data are valuable, they are incomplete in that they exclude Indians eligible for IHS services who are not accessing the IHS system. Even for those Indians seeking IHS services, the data include only the health problems presented by the patient. Thus, through the IHS patient care information systems, it is not possible to calculate true prevalence and incidence rates for the IHS eligible population or to determine their total health care utilization. IHS also lacks complete behavioral information for the IHS eligible population.

Although some large national surveys, e.g., the National Health Interview Survey, do include some reservation and urban Indians in the national sample, they are too few in number to provide estimates for the IHS service population or the Indian population generally. Therefore, even combining Indian data over several years of national survey data does not result in reliable estimates for the IHS service population or the Indian population generally. IHS has attempted to fill these gaps by funding special samples of Indians in national surveys, in particular, the National Medical Expenditure Survey and the National Maternal and Infant Health Survey. However, the cost of such special samples is very high, they are conducted infrequently, and they produce IHS aggregate rather than IHS regional estimates.

NIH and ADAMHA support minority-related research and research training through targeted minority programs and through regular grant and contract programs. These agencies as well as AHCPR need information on minority representation in their extramural research and research training programs. Through the NIH grants administration data system, it is possible to monitor the number of minority researchers who are principal investigators on research grants, and the NIH/ADAMHA Consultant File contains information, including race and ethnicity, on about 8000 researchers who can be used as experts by the two agencies. Improved information also is needed on minority targeted research training programs, such as the Minority Biomedical Support Program and the Minority Access to Research Careers Program.



The National Library of Medicine (NLM) needs more data to improve access by individual health professionals to NLM's information products and services, especially by persons unaffiliated with an institution or who are located in predominantly minority populations. Targeted communities include Black, American Indian, and Hispanic populations. Existing data are neither current across health professions nor complete enough to identify where the target populations are located.

## **CROSSCUTTING DATA ISSUES IN MINORITY HEALTH**

Previous sections of this report have discussed the data needs of PHS agencies in the area of minority health, the minority health data plans and resources developed in PHS to address those data needs, and a number of data gaps in the area of minority health. In addition to identifying data gaps, Task Force review also identified several general data policy issues which require attention if minority data are to be improved.

### **IMPROVING PLANNING FOR MINORITY HEALTH DATA**

To ensure that planned data collection, analysis and dissemination activities are responsive to policy and program needs, it is critical that a clear focus and continuing forum be established for data planning, communication and coordination of minority health data. Because data needs and activities in minority health data are distributed throughout all PHS agencies, a central focus is needed for policy coordination and another is needed for technical leadership. In addition, attention to minority health issues needs to be incorporated into the early planning stages of major surveys and other large scale data activities.

### **ASSESSING THE ROLE OF SOCIOECONOMIC AND OTHER FACTORS IN HEALTH DISPARITIES**

Reliable health data are needed on racial and ethnic minority populations for a variety of reasons. As indicated earlier, however, to fully understand the causes of racial and ethnic disparities in health status and access to care it is essential to consider the impact of socioeconomic factors, such as income, education, and education, as well as the role of health behavior. Analyses sometimes focus on race differences alone, when a more sophisticated and meaningful approach might include socioeconomic measures and other factors relating to economically disadvantaged status as well. Racial disparities are often reduced when these factors are taken into account. Similarly, racial disparities in health are often reduced when individual health behavior is considered. Further, factors relating to recency of immigration, acculturation, and country of birth also help to understand the causes of health disparities.

### **MEASURING RACE AND ETHNICITY**

OMB statistical policy standards outline a uniform set of categories and definitions required for use in all data collections relating to race and ethnicity in federal activities. Task Force review revealed that, while most PHS data activities use these categories, their use is not yet universal. In addition, some agencies are unaware that the OMB standard is a minimum, and

that additional detail and flexibility for race and ethnicity data is possible within that minimum standard.

Further, while PHS data systems do include the OMB standard categories for race and ethnicity, they do not always publish the data for all categories. Data are sometimes aggregated into a category labeled "other races" even when reliable estimates can be made. This practice results in the loss of valuable racial and ethnic detail. In addition, even when data are tabulated in the minimum categories, the categories may vary in such a way as to limit comparisons from one data system to another. For example, Hispanics may be presented as one of the five mutually exclusive race-ethnic categories or as a separate ethnicity category. Improved consistency in race and ethnicity tabulations is needed.

While the OMB standard categories for race and ethnicity are extremely valuable in promoting uniform and comparable minority health data, the categories are broad and some encompass many different subpopulations representing diverse nationalities and cultures. Accordingly, use of the OMB standard may mask major differences in health status within minority populations. For example, 1983-85 data reveal a wide variation in infant mortality rates among Hispanics: from 8.0 among Cubans to 12.3 among Puerto Ricans with Mexican-American mothers having about the same rate (8.8) as White mothers. Variability in infant mortality rates also exist among Chinese, Japanese, and Filipino mothers.

#### IMPROVING ANALYSIS AND DISSEMINATION OF EXISTING MINORITY DATA

While a number of important data gaps were identified by the Task Force, an impressive amount of minority health data already has been and continues to be collected. However, it is not clear that the most effective use has been made of data already collected. Some of the existing data have not been analyzed and presented for minority groups, and some minority data resources are little known outside the sponsoring agency.

Further, while large national surveys like the National Health Interview Survey contain too few minority group respondents in any one year to support separate estimates, combining two or more years of existing data might provide sufficient sample sizes to support reliable estimates for some minority groups such as Hispanics. Much greater attention is needed to the issue of analyzing the data already available.

To be useful for surveillance, policy development and program uses, data must be easily accessible and available to those who need it. Many organizations, planners, and researchers do not know about the existence or availability of minority health data sources. Efforts to promote awareness and availability of current data resources in minority health are limited.

#### IMPROVING DATA COLLECTION ON RACIAL AND ETHNIC MINORITIES

Even if all existing data on minority health were analyzed and available in one place, serious, challenging data gaps would remain for some minority populations and subpopulations. Insufficient attention has been directed to improving the ability of our basic current surveys



and epidemiological activities to develop strategies to ensure the inclusion of sufficient numbers of minorities in study samples to support estimates.

Oversampling strategies may work for some populations, but this approach is not a panacea and a multifaceted strategy is needed. For example, other approaches need evaluation which might involve the addition of minority group followback surveys to existing survey mechanisms, or the conduct of special targeted surveys like the Hispanic HANES or the Survey of American Indians and Alaska Natives. In large scale registries or community based epidemiological research studies, it may be necessary to add study sites which include adequate numbers of minority groups of interest. For some small subpopulations, smaller scale targeted epidemiological studies may offer the best data development strategy.

#### PROMOTING STATE AND COMMUNITY LEVEL DATA

While the Task Force focused primarily on minority data for national policy and program needs, the need for comparable data at the State and community level is equally compelling. Few minority health indicators are available for subnational levels of geographic detail, such as counties and urban areas. Where subnational data are available, they typically conform to recognized political boundaries. When minorities live in communities that do not generally conform to the specific geographic boundaries of political jurisdictions (States, counties, wards, districts, etc), the ability to develop data on minority populations for meaningful geographical groupings such as "communities" or "neighborhoods" is virtually impossible.

#### STRENGTHENING DATA QUALITY

Developing high quality data on the health of minority populations raises challenging methodological issues. The problem of measuring race and ethnicity in a consistent manner across different data systems and over time is a serious one. Different data collection approaches such as self reporting, interviews, and third party administrative records raise issues of completeness and comparability. In addition, persons of mixed racial and ethnic backgrounds have difficulty responding to the standard OMB classification.



## **CHAPTER V**

### **RECOMMENDATIONS**

On the basis of its review, the Task Force developed a number of recommendations for improving minority health data throughout PHS. The recommendations are grouped into eight themes or priority areas dealing with organizing and planning for minority data, improved understanding of the causes of racial and ethnic disparities in health, improving the measurement of race and ethnicity, addressing data gaps through improved analysis and dissemination of existing data as well as the collection of new data, and ensuring the quality of race and ethnic data.

#### **ORGANIZING AND PLANNING FOR MINORITY HEALTH DATA**

1. The Office of Minority Health should strengthen its leadership and policy coordination activities in the area of minority health data across all PHS agencies and activities.
2. OMH should establish an ongoing Minority Health Data Advisory Committee. The committee would serve as a PHS wide forum for continuing communication, coordination, planning and oversight of minority data activities within PHS. The Committee should develop a long-term plan for addressing the most important health data gaps for minority populations.
3. Each PHS agency should designate an agency-wide contact person for minority health data. The individual would serve as the principal resource person regarding minority data plans, issues and activities within the agency, and would maintain liaison with other agencies.
4. The National Center for Health Statistics should establish an organizational unit devoted to minority populations. The unit should be adequately staffed and serve as a central focus for technical leadership, planning, analysis and dissemination of general purpose statistics on minority populations across all Center programs.

#### **UNDERSTANDING THE CAUSES OF RACIAL DISPARITIES IN HEALTH**

5. To assist in fully understanding the causes of racial and ethnic disparities in health status and health care access and use, PHS agencies should include additional questions on social and economic factors as well as race and ethnicity in major surveys, and expand their analyses of existing data relating to the role of socioeconomic factors. Among the factors to be included are education, occupation, income, health insurance and related economic and program participation information.

6. In addition to social and economic factors, behavioral factors are essential to a fuller understanding of the causes of racial disparities in health. Accordingly, PHS agencies should expand the collection and analysis of data on individual risk factor behavior, e.g., cigarette smoking, in major surveys.
7. To better assess health status and health care access issues in diverse minority populations, PHS agencies should include selected questions on acculturation, nativity and recency of immigration in appropriate surveys and studies and include such factors in analyses. In addition, PHS agencies should support further research into the relationship between these issues and minority health.

### **IMPROVING THE MEASUREMENT OF RACE AND ETHNICITY**

8. PHS should publicize and reissue the current Standards for the Collection and Analysis of Racial and Ethnic Data in Federal Agencies (OMB Statistical Policy Directive 15). The standards outline a minimum set of race and ethnic categories and definitions required for use in all federal data collection activities which include race items.
9. PHS should develop and encourage the use of a supplemental set of standards for classifying racial and ethnic subpopulations (Mexican-American, Chinese, etc.) for use in appropriate PHS data activities.
10. As a basis for improvements, PHS should develop a review of the literature relating to methods, issues, and findings in the measurement of race and ethnicity in health statistics activities. Based on the literature review, PHS should convene a workshop or conference devoted to issues in and the development of a research agenda relating to the measurement, analysis and dissemination of racial and ethnic minority health data.
11. CDC/NCHS, in collaboration with OMH, other PHS agencies and the Census Bureau, should undertake a program of methodological research into issues associated with the measurement of race and ethnicity in surveys and research.

### **IMPROVING ANALYSIS AND DISSEMINATION OF EXISTING DATA**

While the Task Force identified a number of significant gaps that can only be addressed through new data collection, much better use should be made of the large amount of data already collected.

12. CDC/NCHS should combine several years of data from the National Health Interview Survey, the National Hospital Discharge Survey, the National Ambulatory Medical Care Survey, the National Vital Statistics System and other data sources to develop and publish periodic comprehensive profiles of the health status and health care use of minority populations in the U.S.

13. CDC/NCHS, in collaboration with OMH, should develop and disseminate a periodic report on the health of minorities similar in concept to Health: U.S. and Mental Health: U.S.
14. OMH should promote the improved dissemination of minority data to appropriate audiences through such existing PHS dissemination mechanisms as Public Health Reports, MMWR, clearinghouses and related approaches.
15. To promote wider availability of minority data, OMH should consider the establishment of a full service, minority health data resource center or archive to assist federal and outside data users in obtaining needed minority data. Modeled after similar data resource centers in other areas, e.g. aging, the center would provide a national resource for major data sets dealing with minority health, analyses and publications, as well as technical assistance.
16. To promote wider analysis of minority health data, PHS agencies should develop aggressive public use data tape release programs, including grant and contract support for data analysis as well as periodic data users conferences.
17. OMH should develop approaches to promoting wider analysis and availability of existing minority data within PHS. Approaches might include the establishment of an internal statistical capability, a statistical resource contractor, a task order contract or other alternatives.
18. OMH should publicize and update the Directory of PHS Minority Health Data Resources on a periodic basis. The Directory was developed by the Task Force as a central reference guide to existing and planned data sources in minority health.

#### **ADDRESSING DATA GAPS THROUGH IMPROVED DATA COLLECTIONS**

Improvements are needed to promote wider analysis and dissemination of existing data on minority health. However, even if all existing data were analyzed and available, significant gaps would remain for some racial and ethnic minority populations and, particularly, subpopulations.

19. PHS should implement a strategy for developing data on racial and ethnic minority populations and subpopulations which consists of several approaches - improving vital statistics, oversampling in national surveys where feasible, conducting followup and dual frame type sampling approaches for special surveys, and sponsoring targeted studies for developing data on subpopulations where oversampling is not feasible or cost effective.



### Vital Statistics and Population Data

20. CDC/NCHS should develop procedures to promote uniform recording, coding and analysis of vital statistics data on additional racial and ethnic minority populations and subpopulations in the U.S. Building on the success achieved in the Hispanic area, NCHS should encourage all States to adopt similar reporting and coding policies for Asian and Pacific Islander vital events, and should follow as closely as possible the eight Asian and Pacific Islander subpopulation categories used in the 1990 Census.
21. CDC/NCHS should continue its evaluation of the quality of reporting of race and ethnicity in the National Vital Statistics program as a basis for improvements in those areas. In particular, CDC/NCHS should work with IHS to improve the accuracy of American Indian race reporting on death certificates.
22. CDC/NCHS should work with the Census Bureau to develop intercensal population estimates on a national and State basis for race and ethnic minority populations and subpopulations to serve as denominator data. In addition, CDC/NCHS should work with the Census Bureau to develop national and State level estimates of social and economic characteristics of racial and ethnic minority populations for intercensal years.
23. IHS, in collaboration with NCHS, should explore with appropriate States the potential for adding information on principal Indian Tribe or Alaska village on the birth and death certificates of appropriate States.

### Health Status, Health Resources, Health Care Use and Expenditure Data

24. To improve the research base on minority health, PHS should consider applying the current NIH-ADAMHA research grants policy on inclusion of minorities in extramural research activities to all PHS agencies.
25. Oversampling for racial and ethnic minorities should be considered in the planning of all major recurring surveys sponsored by agencies of the PHS. Specifically, the National Health Interview Survey, the primary source of national data on self-reported health status, illness, disability and use of health care in the U.S. should oversample Blacks and Hispanics in greater numbers than is currently done.
26. In the planned sample redesign of the National Health Interview Survey scheduled for 1996, attention should be directed to opportunities for oversampling Asian and Pacific Islanders and American Indians and Alaska Natives. If this is not feasible, NCHS should explore other methods of increasing the availability of data for these minority populations. Other potential survey candidates for oversampling opportunities (for Hispanics and Asians) include the planned third cycle of the National Medical Expenditure Survey, future cycles of NHANES, the National Survey of Family Growth, and the National Health Care Survey.

27. Where oversampling is not feasible because of small population sizes or other issues, consideration should be given to the initiation of special surveys based on follow back approaches, special sampling frames and other augmentation approaches using methods comparable to national surveys which would support reliable estimates for minority populations and subpopulations. Research should also be directed at the development of more efficient methods for sampling minority populations.
28. PHS should support targeted, smaller scale surveys and studies to develop data for minority populations and, especially, subpopulations. For most smaller minority subpopulations, this approach should be the primary method for data development. Such studies should employ measurement approaches which will make them comparable to national estimates for the general population. To support these studies, the NCHS Disadvantaged Minority Health Improvement Grant Program should be supported at an adequate level.
29. While the NCHS Disadvantaged Minority Health Improvement Grant Program will be the focal point for support of targeted minority health data development efforts, all PHS agencies supporting epidemiological, behavioral and health services research through extramural grants to individuals, institutions and centers should support minority data development activities through those mechanisms. To promote policy coordination, OMH should review all extramural research grant solicitations dealing with minority health issues.
30. In developing future plans for the family of provider-based surveys which comprise the National Health Care Survey, NCHS should examine the potential for improved and expanded data collection, analysis and dissemination of information on minority populations.
31. NCHS should evaluate the quality and completeness of race and ethnicity data obtained from surveys based on health records, and develop recommendations relating to more accurate, complete and detailed information on race and ethnicity in health record-based surveys.
32. The OMB standard item on race and ethnicity should be included in all uniform health data sets developed or sponsored by PHS agencies.
33. NCHS, in collaboration with OMH and ODPHP, should develop a plan to address minority data needs associated with Healthy People 2000. Data gaps relating to monitoring progress toward the minority health objectives included in Healthy People 2000, as well as data gaps which impeded the development of minority health objectives should be addressed.

34. All agencies of the Public Health Service should examine the potential for expanded data collection, analysis and dissemination of minority health data from existing data systems, whether surveys, surveillance activities, epidemiological studies, registries, or other activities. Specifically:
- ADAMHA should build and expand upon existing profiles of minority populations based on its alcohol, drug abuse and mental health surveys and epidemiological studies relating to the prevalence, correlates and consequences of ADM disorders, the treatment system, the use of services and associated expenditures.
  - In collaboration with OMH, NCHS, AHCPR and IHS should intensify efforts to analyze and disseminate the unique minority data obtained in the Hispanic Health and Nutrition Examination Survey and the Survey of American Indians and Alaska Natives.
  - CDC should promote improved information on minority populations in all of its existing and planned public health surveillance systems and applied research activities.
  - FDA should develop improved information on minority populations in its consumer surveys.
  - AHCPR should improve information on minority populations available from its survey, research, and analytical activities, especially the next cycle of the National Medical Expenditure Survey.
  - NIH should improve the information on minority populations available from its epidemiological research and statistical activities.

#### Health Resources Data

35. HRSA should develop a strategy to improve data on the numbers, geographic distribution and practice characteristics of minority health personnel. The first step would involve the determination of which occupations to focus on, followed by the development of occupation-specific plans.
36. HRSA and AHCPR should support the development of data on health care access and delivery issues for specific racial and ethnic minority groups, including where they receive care, the types of personnel providing care and the effect of the health care provided.
37. HRSA should examine the potential for improved information on minority status in its service recipient populations, its health professions training support programs, its health resource development programs, and its health personnel data activities



## **PROMOTING THE DEVELOPMENT OF STATE AND COMMUNITY LEVEL DATA**

38. NCHS should compile and disseminate State and community level health data with special attention to minority data and Healthy People 2000.
39. NCHS should develop a monograph focusing on guidelines and approaches to small area analysis using national data sets as well as more localized approaches. This monograph should include methodological research on health status measures and indicators for minority populations.

## **IMPROVING PROGRAM DATA ON MINORITIES**

40. All PHS agencies should examine existing and planned program management data systems, whether for research, training or services program administration, for their potential to provide improved data on minority groups. For data systems which do not include information on race and ethnicity, the standard race and ethnic reporting categories should be incorporated into the next planned revision of the respective system. This initiative should be monitored through the OMB clearance process.

## **STRENGTHENING DATA QUALITY**

41. PHS should support methodological studies on issues associated with the collection, analysis and dissemination of data on minority populations. In addition to general methodological issues, attention should be directed to language and cultural factors, as well as health status and health care issues unique to certain minority subpopulations.
42. OMH should work with the Health Care Financing Administration and the Social Security Administration to promote the development of data on minorities in its enrollee and beneficiary populations.



U.S. PUBLIC HEALTH SERVICE

Task Force on Minority Health Data

Appendix

Members of the Task Force

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## PHS TASK FORCE ON MINORITY HEALTH DATA

### Chairpersons

Barbara Favola, Co-Chairperson  
Planning, Evaluation and Legislative Officer  
Office of Minority Health, OASH

Patricia Golden, Co-Chairperson  
Special Assistant to the Director  
Division of Epidemiology and Health Promotion  
National Center for Health Statistics, CDC

James Scanlon, Co-Chairperson  
Director, Division of Data Policy  
Office of Health Planning and Evaluation, OASH

### Members

Agency for Health Care Policy and Research  
Diane L. Adams, M.D., M.P.H.  
Minority Health Coordinator  
Center for Research Dissemination and Liaison

Harvey Schwartz, Ph.D.  
Senior Economist  
Office of Science and Data Development

Alcohol, Drug Abuse and Mental Health Administration  
Delores Parron, Ph.D.  
Associate Director for Special Populations  
National Institute of Mental Health

Sherman L. Raglan, M.S.W.  
Deputy Associate Director for Special Populations  
National Institute of Mental Health

Centers for Disease Control  
Wilma Johnson  
Program Planning and Evaluation Officer  
Office of Program Planning and Evaluation

Rueben Warren, DDS, Dr.P.H.  
Assistant Director for Minority Health

Food and Drug Administration

Felton Armstrong

Director, Division of Management Systems and Policy

Office of the Associate Commissioner for Management and Operations

Sharon Smith Holston

Associate Commissioner for Management and Operations

Health Resources and Services Administration

Jerry McClendon

Director, Office of Data Analysis and Management

Bureau of Health Professions

Ernell Spratley

Program Analyst, Analysis and Evaluation Branch

Division of Disadvantaged Assistance

Bureau of Health Professions

Indian Health Service

Tony D'Angelo

Director, Division of Program Statistics

Office of Planning, Evaluation and Legislation

Richard Kotomori, M.D.

Chief, Special Initiatives Branch

Office of Health Programs

National AIDS Program Office

Art Lawrence, Ph.D.

Director, Planning, Resource Analysis and Information

Services Staff

Valerie Setlow, Ph.D.

Deputy Director

National Institutes of Health

John Ruffin, Ph.D

Associate Director for Minority Programs

Office of Disease Prevention and Health Promotion

Ashley Files

Coordinator, Prevention Policy Staff

Patricia Norris

Communications Advisor



Office of Populations Affairs

Eugenia Eckard

Statistician

Research and Evaluation Staff

Evelyn Glass

Regional Operations Officer

Office of Family Planning

National Vaccine Program Office

Chester Robinson, D.P.A.

Acting Associate Director for Policy and Program Analysis

Office of Health Planning and Evaluation

Nancy Pearce

Chief, Information Collection Management Branch

Division of Data Policy







